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Contents

Chapter 4: Development and Pre-testing of the Revised Parental Illness Impact Scale (PIIS-R)

Chapter 5: Psychometric Evaluation of the Revised Parental Illness Impact Scale (PIIS-R)

Chapter 6: Children of Parents with Parkinson's Disease

Chapter 7: Comparing Children of Parents with Parkinson's, Multiple Sclerosis and Stroke

Chapter 8: Conclusions and Implications for Future Research

References

Appendices

List of figures

List of tables

Instrument Abbreviations

BDI: Beck Depression Inventory

DSRS: Depression Self Rating Scale

EUROQoL-5D: EUROQOL Group Quality of Life Instrument

FCOPES: Family Crisis Orientated Personal Evaluation Scales

FES: Family Environment Scale

IPPA: Inventory of Parent and Peer Attachment

NS-SEC: National Statistics Socio-Economic Classification

PIIS: Parental Illness Impact Scale

PQA: Parentification Questionnaire – Adult

PQY: Parentification Questionnaire – Youth

SEQ: Self-Esteem Questionnaire

SRBI: Self-Report Barthel Index

SSC: Social Support Scale for Children

SSQSR: Social Support Questionnaire Short R

YQOL-R: Youth Quality of Life Instrument

Abstract

Background: The onset of a chronic neurological condition can have a serious impact on the individual's quality of life (QoL). Literature on how this affects the individual's children is sparse, and only a preliminary measurement tool, the Parental Illness Impact Scale (PIIS), currently exists to measure this.

Aims: Further development and validation of the PIIS, and to assess the QoL and psychosocial well-being of adolescent and adult children whose parent has either a chronic or acute neurological condition, and make comparisons across conditions.

Methods: Following an extensive pre-testing programme, questionnaire batteries including a revised version of the PIIS and instruments measuring QoL and psychosocial variables were postally administered to 438 family members where one parent had a diagnosis of Parkinson's disease (PD), Multiple Sclerosis (MS) or stroke. Responses were received from 331 participants (76%). Of these 171 were adolescent and adult children (age range 11-48), 91 were the affected parent, and 69 the non-affected parent.

Results: Psychometric analysis shows the revised PIIS-R to have good construct, concurrent and discriminant validity. Internal consistency (Cronbach's Alpha .92) and test-retest reliability was high. The impact of parental neurological illness was highest in children of stroke patients, and lowest in children of people with PD. Levels of self-reported depression were significantly raised in all three groups. Correlations between child QoL and parental well-being suggest that the emotional manifestations of MS significantly affect children's QoL.

Conclusion: The PIIS-R is a scientifically robust measurement tool with which to assess the impact of parental illness. Both chronic and acute parental neurological illness has an impact on children's QoL and psychosocial well-being, and this needs to be recognised by service providers and in clinical guidelines. The development of effective interventions, information resources, and evidence-based guidelines, will require longitudinal study.

Chapter 1: The Impact of Parental Illness and Disability on Children

(1-1) Introduction: Literature relating to the impact of parental illness and disability on children is relatively sparse (Mukherjee *et al.,* 2002b). There are some notable exceptions. Researchers of children of parents with HIV /AIDS, and cancer have taken the lead in investigating children's responses to their parent's condition, although even in these areas there is a need for longitudinal study (Rotheram-Borus *et al.*, 1997). Additionally there has been a long tradition of assessing the impact of parental affective disorder on children, and particularly maternal depression. It is here we see the greatest strides in this field, with longitudinal data emerging in the last decade.

This narrow focus is beginning to change, with new research emerging on the impact of a wider range of parental conditions, such as Parkinson's disease (PD), inflammatory bowel disease, and chronic back pain. In some neurological conditions however, such as stroke and traumatic brain injury, there is currently little or no data on how this might impact on children's quality of life and psychosocial well-being.

(1-1-i) Aims of chapter: The experimental data within this thesis focuses on three parental conditions; PD, multiple sclerosis (MS) and stroke. The specific aims of the thesis are detailed at the end of this opening chapter, after a selective review and critical analysis of current literature. The aims of this review are:

1. To critically evaluate current literature relating to the impact of parental illness.
2. To identify recurrent themes and issues in children's reaction to parental illness.
3. To identify differences in children's responses to specific parental conditions.

The main focus of the chapter will be on the impact of parental chronic illness, although the chapter will briefly discuss findings relating to parental psychological disorders and parental acute illness. The need to develop further research and how the reviewed literature informed the studies reported in this thesis are discussed following this review.

(1-2) Parental Chronic Illness

As the main focus of this thesis, a detailed discussion of research relating to parental PD and MS is warranted. As two relatively well researched areas this is followed by discussion of the impact of parental HIV / AIDS and cancer, and then the limited data

relating to children of parents with epilepsy, as this appears to be the first parental conditions where an intervention with children is reported. The section concludes with findings from three newly studied conditions; inflammatory bowel disease, arthritis, and chronic back pain.

(1-2-i) Parkinson's Disease: Although Parkinson's disease is commonly regarded as a disease of the elderly, one in seven patients is diagnosed before the age of fifty, and one in 20 before the age of 40 (Koller & Hubble, 1995). Despite this, just two studies have focused specifically on the impact on children of having a parent with PD, and both have limitations. The report compiled for the Parkinson's Disease Society by Roger Grimshaw in 1991 was the first to address the impact of parental PD. In his research Grimshaw focuses on the perspectives of pre-adolescent children aged 5-12, and young people aged 16-24 who have a parent with PD. The work incorporates both new and previously identified factors (Thurman, 1985, Rolland, 1988), including styles of communication and those resources upon which families tend to draw when dealing with change. The report identifies a number of pertinent factors relating to the impact of parental PD. These include children's changing roles, both domestic and emotional, within the family of a parent with PD, as well as changing relationships with both the well and affected parent. Issues regarding children's social and emotional development and well-being, their level of independence, perceptions of disease, and fears for the future are raised in this study. Grimshaw collected data through semi-structured interviews from thirteen participants within family case studies. The qualitative nature of this research is therefore a major limitation, as is the selective nature and small sample size. As the author himself acknowledges, such an approach does not allow generalisations regarding outcomes to be made to a broader population.

In the second study of children of parents with PD, Schrag and colleagues (2004a) address a number of the limitations of Grimshaw's study. A quantitative rather than qualitative approach was taken, and eighty-nine participants, aged from 12 to 48 years completed questionnaires measuring QoL, self-esteem and depression. The sample was divided into two age groups, a younger group aged 12-18 years and an older group aged 19 and above. The QoL, self-esteem, and psychological well-being of the two groups were compared. Analysis revealed that whilst the two age groups did not differ in overall QoL scores, age was implicated in specific aspects of QoL. Younger children reported a significantly heightened sense of burden in relation to their contribution to daily help in the parental home, and far greater difficulty in

dealing with friends' reactions to their parent's condition. Significant associations were found between certain aspects of QoL and specific demographic factors. The authors focused specifically on the variables of age of the child, their age at parent's diagnosis, and the parent's disease duration. Results suggested that the younger the child the greater their perceived burden of daily help, and the greater the degree of difficulty in relationships with friends. Conversely the older the child the greater the recognition of the effects of PD on both their well and unwell parent. A similar pattern was evident when focusing on the child's age at their parent's diagnosis. Again, the younger the child at diagnosis the more pronounced their perceived burden of daily help, and the greater the difficulty with communication, understanding, and coping with friends reactions. Results showed a reduction in overall QoL as disease duration increases, and also in three particular domains. Longer disease duration was associated with worsening communication and understanding, reduced personal development and independence, and increased impact on family functioning. Although no differences were evident between males and females in relation to QoL, females did report lower self-esteem, and higher levels of depression.

The authors point to a number of limitations in their study, including the well documented bias inherent in self-report questionnaires. The sample used in their research was small and self-selected, and might not have been representative of the normal population. Additionally there were no control groups employed in the study (a weakness of much of the research in this area), and therefore it is difficult to draw firm conclusions from the reported data. Despite these limitations the authors conclude that their results suggest a lack of awareness of the needs of both adolescent and adult children when confronted with parental PD, and that further research is necessary to identify other influences on the QoL of children of parents with a chronic illness. This is one of the aims of this thesis, and is reported in chapters 6 and 7.

Schrag *et al.* (2004b) also report on the preliminary validation of an instrument designed specifically to measure the impact of parental illness, the Parental Illness Impact Scale (PIIS). This appears to be the first instrument of its kind, and the authors conclude that the instrument shows satisfactory internal consistency and validity. The limitations of this instrument, in particular the crudeness of construction (as discussed in chapter 4) and sample size employed are recognised by the authors, as is the need for further development and validation of its psychometric

properties. Another aim of this thesis is to undertake further development and evaluation of the PIIS, and this is reported in chapters 4 and 5.

(1-2-ii) Multiple Sclerosis (MS): MS is the most common source of neurological disability in young adulthood (Burgess, 2002). Onset of the condition occurs before the age of 30 in half of those affected, and prevalence peaks at age 45 (Blackford, 1992). At such an age, the person with MS (PwMS) is still working and socially engaged, and is likely to have a young spouse and children at various stages of development. Thus MS places significant limitations on the PwMS's most productive years (Cella *et al.,* 1996), at a time when they are most likely to be playing an active parental role and to be engaged in looking after a family as well as working. As is the case with PD, the challenges facing the PwMS and their families may change greatly from the initial diagnosis to the later more chronic stages of the illness. The unpredictable course of MS, its episodic nature and frequently disabling neurological symptoms are among the many issues that may influence the QoL of the PwMS and their family (Pakenham, 2002).

An increasing number of studies have now investigated the impact of parental MS. Much of the early research with children of PwMS was qualitative in nature, but nonetheless provided valuable insight. The first study was reported by Susan Arnaud (1959), who compared 60 children of PwMS with a control group of 221 children of healthy parents. Arnaud concluded that children of PwMS showed elevated levels of dysphoria, hostility, heightened bodily concerns, constrained personal relationships, dependency longings, and a precocious or false maturity. A number of these results were contradicted by later findings, which indicated that children of PwMS were not unique in many of the characteristics reported by Arnaud, and particularly in relation to bodily concerns and interpersonal relations (Carpio, 1981; Olgas, 1974).

Other early studies include that of Sullivan (1980), who demonstrated the potential impact of parental MS on the family unit, reporting PwMS as greatly hindered in their ability to participate in recreational or school activities with their children. Another study by Yuditsky & Kenyon (1979) incorporated a group interview format, and found that adolescent children of PwMS reported having less time to themselves due to increased responsibility, and fears relating to inheriting MS and the possible deterioration of their parent's health. They also discussed widespread negative feelings towards their parent who had MS, other family members, and friends. Peters

& Esses (1985) used a family systems perspective to study 33 children of PwMS aged 12-18. Using the Family Environment Scale (FES; Moos & Moos, 1980), the authors found that these children viewed their families as having greater levels of conflict, with inferior family cohesion, organisation, intellectual and cultural orientation, and moral and religious emphasis. Alternatively, when compared to 33 controls, no differences were found in domains of independence, expression, control, and achievement and recreational orientation. A number of methodological problems have been identified in this study ranging from sample size to administration of the FES, where there was the potential for parents to influences their children's responses. The small control group was also potentially biased in having been recruited from a religious school.

Such a focus on the family unit and related variables has received further attention in more recent studies. The studies of Yahav *et al.* (2005) and Pakenham & Bursnall (2006) address a limitation of previous studies in their employment of large control groups (156 and 145 respectively), although the sample sizes of children of PwMS remain moderate at 56 and 48 respectively. Yahav and her colleagues report adolescent children of PwMS as experiencing a greater perceived burden of daily help, and more anger and fear than their counterparts with healthy parents. Children in this study also display more 'yielding behaviour', a term used to refer to children giving priority to their parents over developmentally appropriate activities, i.e. spending time with friends. Similar results are reported by Pakenham & Bursnall (2006) with children reporting heightened family responsibility, lower social support and general well-being compared to children of healthy parents.

A small number of recent studies have also focused on children's psychological well-being when confronted with parental MS. Yahav *et al.* (2007) found adolescent children of PwMS reporting significantly higher levels of anxiety and depression than children of healthy parents. Steck *et al.* (2006) report that the risk of such mental health problems is associated with the mental health of both the affected and non-affected parent, and that where both parents report depressive symptoms the prevalence of internalising disorders in their offspring is two to three times higher than that found in the normal population. Similar estimations of increased risk of mental health problems are made by De Judicibus & McCabe (2004), although their study is based on parental rather than self-report. Gender has also been shown to play a significant role in the family's response to MS. Steck *et al.* (2001) report that

daughters of PwMS cope significantly better than do sons, and that mothers and daughters cope more positively with an affected father than do fathers and sons with an affected mother. Whilst this study does not report specifically on psychological well-being, a clear link has been shown between coping and psychological well-being in both adolescents (Merlo & Lakey, 2007) and adults (Mao *et al.*, 2003).

Not all studies report a negative impact when children are faced with parental MS. Based on content analysis of essays about friendship written by 35 children aged 11-15 whose mothers had MS or Lupus, Blackford (1992) concluded that children of PwMS are 'more empathic, and are advanced in friendship concept development compared to the general population'. This, she argues, is in contrast to previous descriptions of children of chronically ill parents who have been described as 'constrained, depressed and antisocial'. As a relatively small sample such findings are difficult to generalise to the normal population, but worthy of further investigation.

The practical needs of children of PWMS have now begun to be recognised. Cross (1999), interviewed children aged 7-14 and concluded that 'children need developmentally appropriate information, reassurance about their effect on parents and their own risk of contracting MS, and discussion of the stress on the family'. Mutch (2005) extends this further in reporting the development of a workshop designed as an intervention to assist young people of PwMS. The development of interventions is a much neglected area and, to the best of the author's knowledge, only one other such intervention has been reported with children of parents with epilepsy (Lannon, 1992), and this is discussed in a later section.

The workshops described by Mutch (2005) address many of the issues raised by Cross (1999). Designed for young people aged 9-14, the workshops focus on the social, emotional and educational aspects relevant to children of PwMS. Specifically children are given the opportunity to meet with others who have a parent with MS, voice and share their emotional concerns, and are provided with information to help them understand the nature of their parent's condition. Having attended the workshop Mutch states that children 'leave feeling less isolated'. To date, however, there appears to be no data regarding whether such interventions have a positive impact on the child's well-being over time. Evaluating their effectiveness would require longitudinal study, but is essential if services are to be expected to meet the considerable cost (as identified by Mutch) of running such programmes.

Whilst the number of published studies relating to the impact of parental MS has increased, the picture remains confused by weaknesses in a number of studies. Some recent studies have addressed an element of the methodological weaknesses of previous studies by employing a control group (i.e., Yahav *et al.*, 2007; 2005). Many, however, fail to do so and still employ relatively small samples. There are also a wide range of variables measured using a variety of methodological approaches, including both qualitative and quantitative data analysis, and proxy and self report. A degree of uniformity in methodology and variables measured would allow for a clearer understanding of the challenges faced by children of PWMS. An aim of this thesis is to address some of these issues, and also to assess the relative impact of parental MS when compared to other conditions, something previous studies have failed to consider.

(1-2-iii) Acquired Immunodeficiency Syndrome / Human Immunodeficiency Virus: Advances in medical science means that increasingly 'the character of acquired immunodeficiency syndrome (AIDS) is changing into a chronic illness' (American Academy of Paediatrics, 1999). A body of literature initially developed relating to the needs of children who themselves became HIV infected. Research focusing on the implications of HIV on the family unit, and specifically the children of parents with HIV, has gathered pace in the last decade in response to rising infection rates worldwide.

Literature relating to the impact of parental HIV first emerged in the mid-nineteen-nineties. One of the first reported studies was that by Black *et al.* (1994) who compared children of HIV infected and non-infected mothers. Whilst the authors reported no differences between the two groups of children, the study has clear limitations. All the children included in the study were infants or toddlers, and the HIV mothers were all in the early stages of their illness, and therefore any psychosocial impact on their children may not yet have been evident. A study by Forehand *et al.* (1997) reported on 137 families where fathers were haemophilic, and 50% were HIV-seropositive. Results indicated that children who have an HIV-seropositive father experience greater levels of internalising problems and have poorer relationships with their mother compared to those with an HIV-seronegative father. However, in relation to school performance, physical functioning, father-child relationship and extrafamilial support, no deleterious effects were found. As with a number of studies

investigating the impact of parental illness, a major limitation lies in this being an unrepresentative sample of the haemophilic population at large, participants having been recruited solely from haemophilia treatment centres.

A further and major contribution to the literature has been made by The Family Health Project, 'a multidisciplinary longitudinal research project designed to examine the psychosocial adjustment of children whose mothers are HIV infected' (Family Health Project Research Group, 1998). A major goal of this group has been to inform public policy and to design clinical interventions. In their first report (Forehand *et al.*, 1998) the authors focus on the psychosocial adjustment of 87 inner-city African-America children aged 6-11 with an HIV positive mother. The children themselves were not infected. As a comparison group 149 children from the same ethnic and socio-economic background but whose mother was not infected were also studied. Results from this study indicated that both groups of children displayed developmental difficulties such as internalising and externalising behaviour, as well as problems with cognitive and prosocial competence. These difficulties were greater in children of HIV infected parents, indicating HIV infection to be an additional stressor to the child's psychosocial development. A weakness of the Family Health Project is that it focuses solely on families from low-income inner-city backgrounds, and as such there is a degree of social disadvantage inherent to these families without the addition of a diagnosis of HIV. Recent research underlines the importance of social support in children's adjustment to parental HIV / AIDS (Lee *et al.*, 2007) something that those from lower SES backgrounds may have less access to. Finally Forehand *et al.* (1998) emphasise that interventions be appropriate to the 'social realities', such as the educational level, of the targeted group.

(1-2-iv) Cancer: Despite advances in cancer treatment, its initial diagnosis 'represents a prototype of acute, extreme stress that confronts many family members' (Compas *et al.*, 1994). Early research focusing on the impact of parental cancer was limited by its qualitative and retrospective nature, and reported children's ability to cope, and strategies employed by them in dealing with their parent's illness (e.g. Wellish, 1979; Issel, Ersck & Lewis, 1990: Lewis 1990; Lewis, Ellison & Woods, 1985). A significant limitation of these studies was the highlighted disparity between parental proxy reports and child self-reports, with children tending to highlight the negative impact of their parent's illness on them, and the parent failing to recognise the implications of their condition for their offspring. Proxy report, and the methodological challenges it raises, are discussed further in the following chapters.

Later work by Bruce Compas and colleagues (Compas *et al.*, 1994; 1996) took a quantitative approach, and focused on children's adjustment at a time closer to their parent's diagnosis. Most prominent in the first report by Compas *et al.* (1994) is that children's gender and age, and the gender of the affected parent are key in the disparities seen in children's levels of anxiety, depression and stress-response symptoms. Adolescent daughters of female cancer patients appear particularly at risk. Objective characteristics of the parent's cancer had limited impact on levels of anxiety and depression in both spouses and children. Rather it was their subjective appraisal of the 'seriousness and stressfulness of the cancer' that was the more significant marker of distress in family members.

In a further publication (Compas *et al.*, 1996) the authors report on the cognitive appraisals and coping strategies employed by the children of cancer patients. In relation to the former, children produced accurate appraisals of the 'seriousness and stressfulness of their parent's cancer', although the authors noted that a requirement for inclusion in their study was that children were 'at least minimally informed about their parent's cancer'. With regard to coping strategies, results showed children perceiving that they had little personal control over their parent's illness regardless of their age. Emotion-focused coping was the strategy most employed, with little use of problem-focused coping. However this use of emotion-focused coping appeared relatively unsuccessful, and was associated with heightened symptoms of anxiety and depression.

In a more recent study, Harris and Zakowski (2003) build on the work of Compas and colleagues in adopting a control group with which to compare distress in a group of adolescents of cancer patients. Against the authors' hypotheses, no significant differences in levels of anxiety and depression were observed between children of parents with cancer and those with healthy parents. Additionally, children of healthy parents showed higher levels of post-traumatic stress disorder-like symptoms. Prior research has shown that adolescence can be a particularly turbulent period of development regardless of the presence of serious parental illness (i.e. Lewis 1990), and the authors argued that their results confirm this. Their results also stress the importance of a positive family environment in reducing levels of distress. As seen in previously discussed studies however, this research suffers from the major limitation of a relatively small sample (27 adolescents whose parent had cancer, and 23 with a healthy parent), and findings cannot therefore be generalised.

(1-2-v) Epilepsy: Concern regarding the impact of parental epilepsy, first became evident in the mid-nineteen-eighties (Lechtenberg, 1984; Lechtenberg & Akner, 1984), and were reiterated by Susan Lannon in her publication of 1992 in which she concludes that 'the special needs of children who have parents with epilepsy should receive more attention'. A review conducted by Ellis *et al.* (2000) highlights how little research has been undertaken specifically on the needs of these children, although there is a body of literature that addresses the impact on the family unit as a result of childhood epilepsy (e.g. Ryan *et al.,* 2003; Shore *et al.*, 2002; Camfield *et al.*, 2001) and epilepsy in adulthood (e.g. Thompson & Upton, 1992; Anderson & Barton, 1990).

Particular themes emerge from the publications of Lannon (1992) and Lechtenberg and Akner (1984). The latter places particular emphasis on issues surrounding disclosure of parental epilepsy to their offspring. Although again limited by sample size (12 families were studied), the authors conclude that 'the least disruptive to children at any age is a frank discussion of what the neurologic problem is and what is being done to control it. Efforts to conceal the problem breed distrust'.

Lannon (1992) reported on one of the first family interventions of its type, developed at the Oregon Comprehensive Epilepsy Program. As Lannon freely acknowledges, the basis for this program was established from the main issues raised by Lechtenberg and Akner (1984), i.e. 'learning about epilepsy, fear of abandonment, transfer of dependence, and fear of developing epilepsy'. The program developed by Lannon and her colleagues attempts to address each of these four areas. First, an individual assessment of each family's needs is made, with the family offered a range of services from education and counselling, through to medication reviews. There is an emphasis on the need to develop a close relationship with the family, and to discuss children's reaction to their parent's epilepsy, even if they are not present. Following an initial meeting the family is invited to prioritise their needs for themselves. As Lannon states 'this empowers them, making them participants in care rather than recipients, and shows respect for their concerns and opinions'. Based on this, families are provided with education, guidance and support to help them adjust and deal with the many issues that a diagnosis of epilepsy can bring.

As with the previously discussed intervention developed for children of PwMS (Mutch, 2005), there appears to be no data regarding the long-term effectiveness of the programme outlined by Lannon. There is one substantial difference between the

two interventions in that the latter incorporates the whole family, whilst the former involves solely the children. The lack of data regarding the effectiveness of each programme does not allow for judgement to be made as to which type of structure is most appropriate, and as such is worthy of further investigation.

(1-2-vi) Inflammatory Bowel Disease: Inflammatory bowel disease (IBD) is a chronic illness of unknown aetiology, characterised by recurrent abdominal pain, diarrhoea, constipation, fatigue and weight-loss, frequently linked with stress or anxiety. Investigation into the impact of parental inflammatory bowel disease (IBD) has been undertaken only relatively recently by Mukherjee and colleagues (2002a; b). In the first of their publications they report on a relatively small exploratory study in which they assess the experiences, both positive and negative, of parents with IBD. On a positive note, parents report the development of closer relationships with their children, and a heightened sense of compassion and understanding towards those who are unwell. Amongst the more negative findings, the authors report parents experiencing feelings of worry and guilt, and, in a small number of cases, bouts of depression as a result of the constraints placed upon them by their symptoms. Parents reported their children as reacting with frustration and anger to constraints, such as 'restrictions in social activities', and anxiety when the parent was experiencing symptoms or in hospital. The authors highlight the importance of health professionals providing support for patients and their families.

A further study by Mukherjee *et al.* (2002b) explored directly how children themselves viewed their parent's IBD, its impact on their daily life, coping strategies employed, and what support their family required. Whilst some children appeared relatively unaffected by their parent's illness, others reported feelings of 'sadness, worry, anger and guilt'. The negative impact on daily life included restricted social activities, having to maintain good-behaviour, and withdrawal and irritability on the part of the ill parent. Positive effects included heightened independence, family closeness, and spending time with the parent when ill. Whilst most did not feel additional support was necessary, some expressed a desire for more information and the opportunity to meet others in a similar situation. As another example of a relatively small qualitative study (23 participants aged 6-20 years), it would be unwise to generalise about the authors findings.

(1-2-vii) Arthritis: An exploratory study by Barlow and colleagues (1999) highlights the paucity of data in relation to the impact of parental arthritis. Arthritis has been

shown to be the single biggest cause of disability in the United Kingdom (Pincus *et al.*, 1984), and whilst its impact on carers has been well demonstrated (Jacobi *et al.*, 2003; das Chagas Medeiros *et al.*, 2000; Riemsma *et al.*, 1999), the impact on children appears to have been limited solely to the study by Barlow *et al.* The study is limited in that is does not asses the children themselves, but rather focuses on parental reports of how their condition affects their ability to fulfil a parenting role. It does however provide a starting point with which to assess the impact of parental arthritis. Parents reported feelings of guilt, anger and frustration at their perceived inability to fulfil their parental role, but more positively emphasise the 'bonus' of being able to spend a greater amount of time with their children. Additionally, mothers reported that their children showed a greater awareness of the effects of the disability, and were 'more independent, caring and sensitive'. The authors recognise the potential bias in their sample, and highlight the need to include children and physicians in future work of its kind.

A further study by Katz, e*t al.* (2003) reports the development of a questionnaire to assess disability in parenting in a sample of mothers with rheumatoid arthritis. Using this instrument the authors show that it is mothers of very young children (age 0-5) who report the greatest difficulty in their parental role, this largely relating to psychological distress. The study is limited by a relatively small sample size of 53, of which only seven were mothers of children aged 0-5.

(1-2-viii) Chronic back pain / injury: Although no research has directly involved children of parents with chronic back pain, a recent paper by Strunin & Boden (2004) provides some evidence of its impact through qualitative analysis of telephone interviews with the injured parent. In their assessment of both males and females absent from work for one month or longer, parents discuss the effects of their injury on their physical and emotional relationships with their children. Themes include increased responsibility for children, changes in parental behaviour such as increased irritability, and the inability to be involved in activities with children. These are experienced as a loss on the part of both mothers and fathers. Although not directly involved in the study, the authors speculate that the children would also experience this loss.

With a large sample of 414 participants the study makes a valuable initial contribution to understanding the impact of parental chronic back pain on children, although further research is required to directly assess the views of children themselves.

Strunin & Boden make clear that as back pain is a major problem in most countries, i.e. a prevalence rate of 17.6% in the United States (Guo *et al.,* 1999), its consequences usually focus on the workplace, and includes benefit and medical costs, and lost productivity. The social, less visible consequences are not as well recognised. The authors recommend that 'more attention should be paid to social structural factors such as the provision of medical services and social support to reduce the impact of chronic back pain on the family members'.

(1-3) Parental Psychological Illness

This section opens with the most widely researched of parental psychological illness, that of affective disorder. The section then goes on to discuss two relatively new areas of research; schizophrenia, and obsessive compulsive disorder.

(1-3-i) Parental Affective Disorder: Rates of depression have continued to increase in recent decades (Compton *et al.*, 2006; Klerman & Weissman, 1989), and prevalence of depression in adults in the general population is estimated at 5%-10% (Singleton *et al.*, 2001). A study by Kessler *et al.* (1994) reported a sample aged 15-54, with 14.7% of men and 24% of women experiencing a diagnosable mood disorder at some point in their lifetime. A major depressive episode within the past year was also reported by 13% of women. Current levels of major depression, i.e. within the last month, have been shown to be 3.8% in males and 5.9% in females (Blazer *et al.*, 1994), and research has consistently shown that depression is twice as prevalent in females as males. Nearly 25% of women experience major depression during their lifetime, with adolescence or early adulthood the most prevalent period (Hammen, 1997).

The link between parental depression leading to increased risk of psychopathology in their offspring is well established (Beardslee *et al.*, 1998), and continues to be the subject of much research. In their review of a decade of research, Beardslee and colleagues (1998) report that children of affectively ill parents are 'more likely to exhibit general difficulties in functioning, increased guilt and interpersonal difficulties, as well as problems with attachment'. The authors also highlight that the risk of children developing affective disorder during childhood and adolescence is associated with genetic factors, breakdown in parenting skills, marital difficulties and the severity of the parental disorder. Importantly, unrecognised depression during this period of development can lead to poor educational attainment and psychosocial outcomes, as well as continued depressive disorder in adulthood (Birmaher *et al.*,

1996). This highlights the need for its detection and treatment, and recent data indicates that at least 12% of adolescents report a minimum of minor depression (Sihvola *et al.*, 2007). However, depression in childhood and adolescence frequently goes undiagnosed (Kramer & Garralda, 2000), and this is compounded by the fact that adolescents are unlikely to consult their GP about mental health problems (Potts *et al.*, 2001).

Early investigations into the impact of parental affective disorder were limited to cross-sectional studies, and findings varied widely. Beardslee *et al.* (1998) emphasise the importance of longitudinal research as a means of assessing the immediate and long-term impact of parental affective disorder, and to identify risk factors and predict outcomes. Indeed it is this longitudinal research that has made a significant contribution to the literature in recent years, with studies consistently showing that children of affectively ill parents are at increased risk of depression themselves in adulthood when compared to children of unaffected parents (Hammen *et al.*, 1990; Beardslee *et al.*, 1993; Weisman *et al.*, 1997). Children raised with an affectively ill parent have been shown to have as high a risk as 40% of developing major depression by age 20, rising to 60% by 25 years of age (Beardslee *et al.*, 1993). Strong evidence also exists that the younger the parent at onset of depression the greater the risk to their offspring (Weissman *et al.*, 1988; Grigoroui-Serbanescu *et al.*, 1991). Longitudinal studies such as these remain the 'gold standard' for research, and there is a clear need to incorporate such methodology in future investigations across any parental condition that has the potential to impact on patient's children.

(1-3-ii) Schizophrenia: Early research reported that birth rates were markedly lower in schizophrenic patients, but an increase in rates were observed as a result of the wide-scale process of deinstitutionalisation of such patients, evident in the past 40 or so years (Erlenmeyer-Kimling *et al.*, 1969). Research is now starting to emerge that demonstrates not only the increased risk of psychopathology in children themselves (Ross & Compagnon, 2001), but also the social, emotional and developmental consequences of having a schizophrenic parent.

Although limited by sample size (39 participants), the retrospective study of Caton *et al.* (1998) provides valuable insight into the potential effects of growing up with a schizophrenic parent, the majority in this particular sample being a schizophrenic mother. Offspring reported experiences of being frightened, embarrassed, and in many cases the subject of excessive physical punishment as a manifestation of their

parent's schizophrenia. Additionally a number of children reported having to care for their schizophrenic parent, helping with daily household activities, and giving up 'work or school activities'.

Caton and her colleagues make some key recommendations based on their findings. First, although virtually all the children in this study were brought up by their schizophrenic parent at some stage during their childhood, on average they were raised in three different settings, grandparents and aunts being the most common providers of alternative care. The authors therefore recommend involvement of the extended family in any rehabilitation programme. Secondly, the authors emphasise that whilst the children in their study were aware of their parent's illness, their degree of understanding, and contact and access to health professionals differed greatly, a finding common to other parental conditions (e.g. Schrag *et al.*, 2004). The authors suggest 'education about psychiatric illness should be made available to offspring whenever they express an interest'.

(1-3-iii) Obsessive Compulsive Disorder: Black and colleagues (2003) reported on the first study to assess the impact of parental obsessive compulsive disorder (OCD) on children's behavioural and emotional competence. Previous work by this group highlighted the 'devastating impact of OCD on family and marital life' (Black *et al.*, 1998), as well as causing problems with communication within families. This is also seen in many other families of patients suffering psychiatric illness (e.g. Miller *et al.*, 1986).

Although limited by small sample size and potential sample bias, Black *et al.* (2003) report some important findings from their preliminary results. First they recognise the possibility of genetic transmission in relation to the early development of anxiety and mood disorder observed in their sample of children, which may or may not develop into 'full-blown' OCD. Secondly, and potentially of more interest to service providers, they highlight the possible influence that living with an OCD parent might have on a child's emotional well-being, 'or at least provide modelling of dysfunctional behaviours'. Using logistic regression analysis the authors report higher scores on the Child Behaviour Checklist (Achenbach, 1991) as predictive of the child developing OCD. Other predictors include inappropriate affective responsiveness and poor behavioural control on the part of the OCD parent. Interestingly, they also report female parental OCD as a predictive factor, although they are unable to offer any explanation for this finding.

(1-4) Parental acute illness:

This section focuses on the two acute conditions that have been the focus of research to date, namely stroke and spinal cord injury (SCI). The former is one of the conditions explored within this thesis, and is an area that has only recently received attention.

(1-4-i) Stroke: At the outset of the research reported in this thesis there was no data relating to the impact of parental stroke. However recent findings reported by Visser-Meily and colleagues (2005a; b) have made an important initial assessment. In the first of their studies (Visser-Meily *et al.*, 2005a) the authors report on a sample of 77 children, aged 4-18 years, of 55 parents admitted to an inpatient rehabilitation stroke unit. At the outset of their parent's rehabilitation 14% of children reported at least mild depression, with parental proxy reports identifying 30% as displaying internalising problems and 17% externalising problems. After two months these rates had changed to 7%, 10%, and 15% respectively, and analysis suggested that positive adjustment was associated with the level of strain on the non-affected parent, and was independent of the affected parent's stroke severity, or the level of support offered by the rehabilitation team.

In the second of their studies Visser-Meily *et al.* (2005b) report again on these children's adjustment in making a further assessment 12 months post parental stroke. As seen in the first of their studies, children's functioning showed an improvement between admission to the rehabilitation unit and two months later, apart from in externalising behaviour. The opposite trend was observed at the 12 month period, with a relative decrease in the levels of functioning observed at 2 months. Specifically 12% of children reported at least mild depression, with 16% displaying internalising problems, and 15% externalising problems. These differences between time points, however, are not statistically significant. The authors use a family systems perspective, as first proposed by Rolland (1988), to explain their findings. The initial distress at the parent's stroke is viewed as a form of trauma, and is then followed by a period of adjustment in which the parent is absent from the family home whist undergoing rehabilitation, and psychosocial well-being may improve. The point at which the parent returns home, and the realisation that family structure and routines may require significant adjustment, some of them permanently, leads to a subsequent decrease in psychosocial well-being.

Visser-Meily *et al.* further report that their data suggests that the strongest predictor of children's adjustment is their level of functioning at the time of their parent's stroke, and, as viewed at the 2 month assessment, the psychological well-being of the healthy parent is also a significant factor. The authors also found that gender and age of the child are predictive of adjustment, but do not make clear whether it is males or females, younger or older children who are at greatest risk.

A number of limitations exist, and many are recognised by the authors. The sample size is moderate and this may be the reason why a number of results are not significant. The research also fails to consider a number of likely important demographic variables, including sibling support and family structure (i.e. one versus two-parent families). The two studies also fail to incorporate a control group. The importance of this first assessment of children of stroke patients should not be underestimated however. One of the aims of this thesis is to make a further, more detailed assessment of the impact of parental stroke, and address some of the limitations discussed above.

(1-4-ii) Spinal Cord Injury: Whilst a number of studies report the impact of SCI on children as patients and also their long-term outcomes (e.g. Anderson & Vogel, 2002; Spoltore *et al.*, 2000), only three studies appear to have focused specifically on the impact of parental spinal cord injury on children. Although some 20 years apart the two complement each other in their focus of investigation. Buck and Hohmann (1981) focus on the 'personality, behaviour, values and family relations of children of fathers with SCI'. The authors conclude that children in their study were 'well adjusted and emotionally stable' and that 'family relations were not found to be adversely associated with the disability status of the father'. The authors recognise limitations with this study in terms of its retrospective nature.

A later study by Alexander *et al.* (2002) reports on the impact of maternal spinal cord injury on marital, family and child adjustment. Here, the authors draw similar conclusions based on the 31 children included in their study; maternal SCI 'does not appear to affect their children adversely in terms of individual adjustment, attitudes towards their parents, self-esteem, gender roles, and family functioning'. However, the authors acknowledge that mothers in their study came from higher than average socio-economic, educational, and employment backgrounds, and therefore may have had access to more resources to help cope with the demands of parenting. An earlier study by Westgren & Levi (1994) assesses the effects of SCI on a mother's ability to

provide adequate care for children, concluding there are no grounds 'to question females with an SCI in their roles as parents'. This study is again limited by its small sample size, only assessing ten children, and by its descriptive nature. Although the three studies reported here all follow a similar pattern of results, all are limited by sample size and sample bias.

(1-5) Discussion:

The aims of this chapter have been to critically evaluate current literature relating to the impact of parental illness, uncover recurrent themes and issues which emerge when children are confronted with parental illness, and identify differences in children's responses to specific parental conditions. In evaluating the current literature it is clear that a number of studies suffer from weaknesses such as small and non-representative samples, and few employ control groups. The range of variables measured is wide as is the methodology employed. Few parental conditions have been the subject of longitudinal investigation, and it is therefore unclear as to how the impact of most conditions affects children over time.

Recurrent themes identified include changing roles and heightened responsibility, as well as limitations placed on social activities, and the subsequent harm this has on social development. Emotional well-being is also a consistent theme, with depression and anxiety frequently highlighted. Issues of independence also emerge, and in the majority of parental conditions it is the negative impact on children's independence that is reported. Issues regarding provision of information to children are also frequently raised.

From the studies discussed, it also appears that not all parental conditions affect children similarly. Children of parents with spinal cord injury appear particularly well-adjusted to their parent's condition (Buck & Hohmann, 1981; Alexander *et al,* 2002), although this is surprising in light of the devastating nature of such a life changing injury. Similarly there is some research suggesting children of PwMS adjust well to their parent's condition (Blackford, 1992), and children of parents with inflammatory bowel disease report some positive as well as negative effects regarding their parent's condition (Mukherjee, 2002b).

Some parental conditions have yet to be investigated. For example there is little recognition of the potential impact of parental traumatic brain injury (TBI). Individuals with TBI are subject to prolonged distress, which relates more to the everyday coping

with disability rather than the severity of the initial injury (Florian *et al.*, 1989). Permanent changes in personality and behaviour are common (Kreuter *et al.*, 1998), particularly in younger individuals (Thomsen, 1984), and studies have underlined the potential impact of TBI on both spouses (Rosenbaum & Najenson, 1976) and caregivers (Kolakowsky-Hayner *et al.*, 2001). However, there is little emphasis on the potential impact on children of parental TBI, despite the highest frequency rate being in young adults (Williamson *et al.*, 1996), and therefore those most likely to have a parental role. A small number of studies, however, do recognise the influence on the family unit following TBI. For example, Florian and colleagues (1989) highlight the complexities and uniqueness of problems facing families following head injury, whilst Kolakowsky-Hayner *et al.* (2001) report that the needs of the family extend far beyond the acute phase. The authors of this study conclude that 'the importance of appreciating long-term family needs and other life quality issues should not be underestimated'.

As with a number of conditions discussed in the review the impact of parental PD and stroke has only recently received attention. As stated previously, one in seven PWP are diagnosed before the age of fifty, and one in 20 before the age of 40 (Koller & Hubble, 1995). In Western countries, approximately 5% of all strokes occur in young adults aged below 45 years, although this figure rises to between 19% and 30% in developing countries (Marini *et al.*, 2001). At such an age the impact of both conditions is likely to have a significant impact on the functioning of the family unit, and on any children within that unit. One of the central aims of this thesis is to expand on the initial work of Schrag *et al.* (2004a;b) and Visser-Meily *et al.* (2005a;b), and make a more detailed assessment of the impact of parental PD and stroke.

As previously mentioned, the literature reviewed highlights that research conducted with children of affected parents assesses many different variables, and uses a widely differing range of measures. This emphasises the need for a measurement tool that can be used across a variety conditions. Currently it is difficult to draw conclusions as to the generic needs of children when faced with parental illness and those that are specific to the parental condition. The child experiencing the sudden onset of a parental acute insult, such as stroke or spinal cord injury, may require very different assistance than might the child of a parent with chronic progressive illness such as PD or MS. There are also likely to be important subtle differences between chronic conditions that need to be considered dependent on the specific course and

nature of the condition in question. A further aim of this thesis is to make an assessment of this in comparing children of parents with PD, MS and stroke.

(1-6) Aims of thesis: The aims of this thesis are therefore twofold:

- Further development and validation of the Parental Illness Impact Scale (PIIS), designed specifically to measure the impact of parental illness.
- To assess the QoL and psychosocial well-being of adolescent and adult children whose parent has PD, and make comparisons with an alternative chronic neurological condition of earlier onset, MS, and an acute neurological condition, stroke.

(1-7) Outline of thesis: There follows two further introductory chapters in support of the experimental chapters contained within this thesis. As the ongoing development of the PIIS has been constructed around a QoL model, chapter 2 explores the concept of QoL and its increasing importance in outcomes research. A section of the chapter is devoted specifically to QoL measurement in children and adolescents, as the latter are a major focus of the data presented in later chapters. Chapter 3 goes on to provide an overview of methods and techniques employed in the design and administration of survey instruments, with particular attention paid to those methods employed in the further development and validation of the PIIS.

The thesis contains four experimental chapters. The first two of these detail the further development of the revised parental illness impact scale (PIIS-R). Chapter 4 describes the development and pretesting of the instrument, whilst chapter 5 focuses on the subsequent psychometric evaluation. Chapter 6 goes on to discuss the impact of parental Parkinson's disease on adolescent and adult children. A number of factors are assessed including QoL as measured by the PIIS-R, psychosocial and sociodemographic variables, and also the relationship between parent and child well-being. Chapter 7 then makes comparisons between adolescent and adult children of parents with Parkinson's and those of parents with MS and those whose parents have suffered a stroke.

The concluding chapter, chapter 8, summarises the research presented, including its limitations, and highlights implications for future research and policy. In particular the chapter focuses on implications for service providers, and the need for longitudinal study as a means of developing effective interventions.

Chapter 2: Quality of Life: Concept and Measurement

(2-1) Introduction: The advances of society during the last century and into the new millennium have inevitably led to rising expectations in many spheres of life, and none more so than in relation to health. A natural progression has ensued from viewing health purely as the state of survival, through a period of seeing it as being free from disease, with further advances towards viewing it as the ability to execute activities of daily living (McDowell & Newell, 1996). A more recent development has been to emphasise the importance of psychosocial well-being and quality of life (QoL). The World Health Organisation (WHO) has, for a great many years, advocated that health be seen in a far wider context than simply the 'absence of disease and infirmity'. Good health should be indicated by 'complete physical, mental and social well being' (World Health Organisation, 1958). It is interesting therefore to note that these are the very concepts that underpin what we now refer to as QoL.

The progression noted above is also reflected in standard taxonomies of health such as those published by the WHO. The original International Classification of Impairments Disabilities and Handicaps (World Health Organisation, 1980, figure 2.1), failed to consider the importance of personal and environmental factors. The recently revised model (figure 2.2), the International Classification of Functioning, Disability and Health (ICF; World Health Organisation, 2001) now takes such factors into consideration. This results in a less linear model, and recognises the interactional nature of factors that contribute to individual well-being.

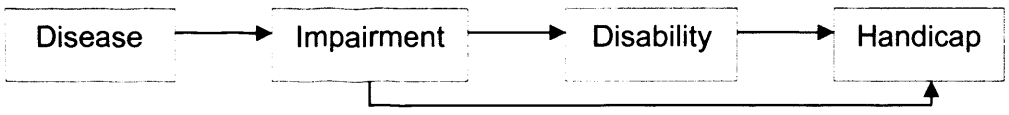

Figure 2.1: International Classification of Impairments, Disabilities and Handicaps

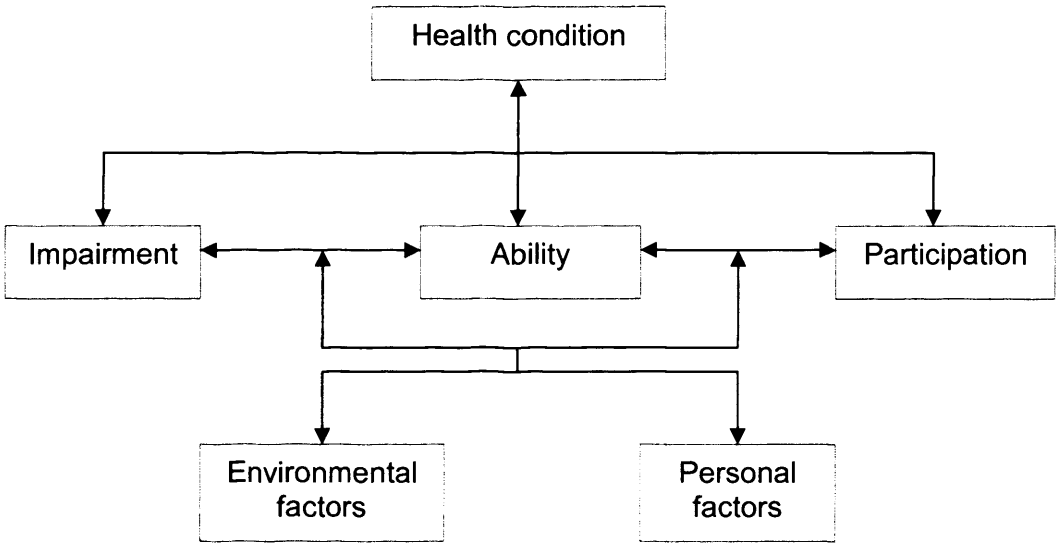

***Figure 2.2*:** International Classification of Functioning, Ability and Health

In a relatively short period of time the ICF has become an internationally recognised conceptual framework (Stucki *et al.*, 2007), and one that appears compatible with both patient's and clinician's understanding of functioning (Dahl, 2002). With specific relevance to QoL, the ICF moves away from previous assumptions that QoL is dependent on level of impairment (Walker & Littlejohn, 2007), and has been applied to a number of conditions, including those relevant to this thesis, such as Parkinson's (Morris, 2006), MS (Khan & Pallant, 2007) and Stroke (Schepers *et al.*, 2007).

(2-1-i) Aims of chapter: The focus of chapters 4 and 5 of this thesis are the further development and validation of the Parental Illness Impact Scale (PIIS). This instrument was constructed around a QoL model in recognition of the increasing importance placed on this concept (Harding, 2001), and was designed to be administered to both adolescent and adult children. The aims of this chapter are therefore twofold:

1. To evaluate the concept of QoL and approaches taken in its measurement.
2. To highlight issues in QoL measurement specific to children and adolescents.

(2-2) Concept and definition of quality of life: In the early 1990s Lesley Fallowfield published her book 'The Quality of life: The Missing Measurement in Health Care' (Fallowfield, 1990). In her opening chapter she states that 'conceptually quality of life

is a somewhat vague term'. More than a decade on, and despite many advances in QoL research, there is still much disagreement and no overriding consensus on a universally agreed definition (Moons *et al.*, 2006). It is worth noting that the apparent preoccupation with agreeing on an accepted definition is not shared by all. Wallander *et al.* (2001) point out that as a hypothetical framework such constructs do not usually enjoy a widely accepted definition, and that 'reasonable minds will have reasonable disagreements as to "the best" definition'. Alternatively, it has been argued that in the absence of a clear definition of QoL, its measurement is scientifically dubious (Hunt, 1997).

(2-2-i) A multidimensional concept: There is general agreement amongst researchers that QoL is a multidimensional concept, relevant to all individuals in society, be they young or old, and regardless of culture or social position. As an example, a relatively early model of QoL put forward by Felce and Perry (1995) proposes the five principle dimensions of physical well-being, material well-being, social well-being, development and activity, and emotional well-being. Such dimensions are generally reflected in most models and regarded as significant in how an individual perceives their own QoL. More recently there has been a move towards the inclusion of spirituality, religion, and personal beliefs as an additional dimension (WHOQOL SRPB Group, 2006; O'Connell & Skevington, 2005), although it has been suggested that this requires further investigation due to difficulties in its measurement (Molzhan, 2007; Moreira-Almeida & Koenig, 2006).

The World Health Organisation Quality of Life Group (WHOQOL) proposes the definition: 'Quality of Life is defined as individuals' perceptions of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the persons' physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of the environment' (WHOQOL Group, 1995). The United Nations also emphasises the importance of such aspects in particular relation to children, in recognising they have the right to 'the highest attainable standard of health' and 'to a standard of living adequate for the child's physical, mental, spiritual, moral, and social development' (Newell, 1993), all of which form dimensions of QoL.

(2-2-ii) Subjective and objective indicators: QoL includes both objective and subjective domains, the former focusing on what an individual can actually do, the latter emphasising the individual's perception. Cummins (2000) explores the relationship between objective and subjective indicators and concludes that both can independently make valuable estimates of QoL as a construct. Whilst the majority of definitions emphasise the subjective element of the concept, it is this very component in QoL research that had originally lead to it being met with a degree of caution by some (e.g. Yeh, 1996). Indeed, at its most extreme, a few, such as Hatton (1998), suggested abandoning the QoL approach all together due to 'insuperable problems in assessing subjective indicators'. This is very much minority view, and it is clear that since the late 1980's the QoL approach, although problematic, has been regarded as of increasing value. This is particularly so in assessing the impact of chronic illness on the individual, and measuring the efficacy and outcome of medical care (Moons *et al.*, 2006). However, in light of the discussed lack of a clear and widely agreed definition of the concept, the prospect that QoL measurement might form the basis of resource application and prioritisation has alarmed some (Jenkinson, 1999; Hunt 1997).

(2-3) Measurement approaches: The evolution of QoL as a conceptual model upon which to base judgements on the efficacy of medical intervention started with measures that were mainly focused on level of function, such as The Health Status Index (Kaplan *et al.*, 1978), and Walker and Greene's (1991) Functional Disability Index. Eiser (1996) refers to such approaches as 'deficit centred models', and clarifies this by stating that 'within the medical context QoL has been equated with functional status, with emphasis on the individual's level of functioning and capacity to fulfil basic self-care tasks'. That is not to say that this is an unimportant dimension, rather functional status is just one of many important components of a QoL approach. The author goes on to recognise the fundamental importance of the subjective side of QoL measurement in stating that 'the individual's assessment of the difficulty and meaning to him or her is paramount'.

It is clear now that the rigid focus on measures of functional disability and health status has moved on to a more rounded and inclusive QoL approach, although there still remains much diversity. Early disease specific measures, which aimed to quantify functions of clinical significance in relation to a specific illness and / or its treatment, have since become the catalyst for what are now termed health-related quality of life (HR-QoL) instruments. Spieth and Harris (1996) define HR-QoL as 'the

subjective and objective impact of dysfunction associated with an illness or injury, medical treatment and health care policy', and as such measures of HR-QoL are designed to measure the impact of a range of medical conditions.

The recognition of QoL as a valuable indicator for the healthy, and not just those suffering from illness, has led to the development of so called 'generic' measures, which aim to assess health in the general population, and measure QoL from a global perspective, as reflected in, for example, the Felce and Perry (1995) and WHOQOL (1995) models. It is apparent though that some generic measures cannot reflect certain elements that are disease specific (Murrell, 1999). Cummins (1995) however, argues that 'it is imperative that all definitions of quality of life be referenced to the general population both in their conception and operational measures'. Other arguments aside, it is clear that the use of generic instruments allows for comparisons across differing cultures and a range of conditions, be they medical or societal (Harding, 2001). Additionally Wallander *et al.* (2001) argue solely for the use of generic instruments with children and adolescents, and make a compelling case for the complete abandonment of the HR-QoL approach altogether. The authors argue the benefit of viewing 'QoL as a construct that is applicable across all children. No differentiation should be made between those who have specific health conditions, any health conditions, and no health condition. That is, standards for a life of quality cannot depend on the challenges a young person experiences. Those standards must be universal'.

(2-4) Measurement principles: As discussed QoL instruments can be disease specific, health related or generic measures. Regardless of which type of instrument is being used, or indeed being developed, the underlying principles remain the same. That is, the instrument must reflect the perceptions of the individual themselves, with minimal input from clinicians or others. Thus the most effective measures are self-administered, simple to understand and easy to answer (Dahlof, 1996). The development of scientifically sound questionnaires is underpinned by long-standing psychometric principles (Thompson, 2000), and this is discussed in detail in the following chapter.

Literature has consistently highlighted the necessity to employ such principles, and a number of authors have identified a lack of psychometric data for many instruments that are regularly used (i.e. Cremeens, *et al.*, 2006; Pal, 1996; Hays, *et al.*, 1993). In an attempt to address such shortcomings the Scientific Advisory Committee of the

Medical Outcomes Trust (2002) proposes guidelines by which to review QoL instruments, which include psychometric properties. They propose the eight key attributes of conceptual and measurement model, reliability, validity, responsiveness, interpretability, respondent and administrative burden, alternative modes of administration, and cultural and language adaptations as a criteria against which to evaluate measures. A number of these attributes are also discussed in the following chapter.

The previously discussed multidimensional approach to QoL is also relevant to its measurement. In efforts to reduce variability and decrease the effect of idiosyncratic responses to specific items, questions are often grouped and analysed as dimensions. Such a grouping can be based on factor analysis, and / or empirical findings. The former, when using both of these processes, serves as a tool in confirming those dimensions deduced through empirical study (Dahlof, 1996). Fayers and Hand (1997) sound a note of caution when employing factor analysis, stating that it is unreliable for use in validating those scales that contain causal indicators, (i.e. items that relate to treatment side-effects or disease symptoms), and should only be used with effect indicators (those that reflect the QoL of the individual). More recent research suggests that factor analysis is appropriate in distinguishing between the two types of item, although it is still not clear whether both can be aggregated to provide a global QoL score (Boehmer & Luszcznska, 2006). Factor analysis is discussed in greater detail in following chapters.

(2-5) QoL life measurement in children and adolescents: The following section focuses specifically on QoL measurement in children and adolescents, and highlights particular issues in assessing the well-being of this particular group. Wallander *et al.* (2001) view QoL as an 'overarching concept' for this period of development, and that there is 'considerable diversity in conceptualisation of an operational approach' to QoL in childhood and adolescence, and the 'confusion' that can result when utilising a QoL approach. Meuleners, *et al* (2003) draw further attention to this in reporting that there appears no widely agreed definition of QoL for young people, although suggest that this can be measured by 'five underlying constructs namely social, environment, psychological, health and opportunities for growth'.

The apparent lack of agreement on a definition of what constitutes QoL for young people is even more apparent when focusing specifically on HR-QoL. Two recent reviews present opposing conclusions. De Civita *et al.* (2005) conclude that there is

still no overriding consensus, whilst Ravens-Sieberer *et al.* (2006) suggest there is now broad agreement. Following a thorough examination of current instruments and a literature review Ravens-Sieberer and her colleagues identify what they regard as the major HR-QoL dimensions for children and adolescents and these are summarised in table 2.1. The authors make clear that no single instrument measures all of the components identified, but that 'the assessment of important dimensions for a particular investigation goal seems possible'.

	Dimension	Additional Descriptors
1.	Physical well-being	Physical health, complaints, pain, physical functioning, mobility
2.	Psychological well-being	Mental health, satisfaction, moods, positive and negative emotions
3.	Energy and vitality	Potentially a function of dimensions 1 and 2
4.	Self perception	Self-esteem, body-image, and perceived physical appearance
5.	Cognitive functioning	Functional cognitive ability, cognitive school functioning, school well-being
6.	Social functioning and support	Relationships with friends / sex life, family well-being (including family / household roles, relationships with parents)
7.	Autonomy and independence	
8.	Psychosocial relations to the material environment	Including characteristics of the environment itself
9.	General health perception and life quality	

Table 2.1: Major Components of HR-QoL for Children & Adolescents (Ravens-Sieberer *et al.*, 2006)

(2-5-i) Methodological issues specific to children and adolescents: There are fundamental differences between childhood and adulthood that raise a number of conceptual and methodological issues when measuring QoL. Childhood and adolescence is a period of development in which there are immense changes from a mental, physical and social perspective (Lindstrom & Eriksson, 1993), and these were not initially recognised in early investigations (Eiser & Morse, 2001a). Effective measurement of young people's QoL therefore requires consideration of the age and developmental stage of the child and the associated cognitive and emotional changes (Reinfjell, *et al.*, 2006), and also the range of social contexts (i.e. school, peer group, community) that are likely to influence QoL at this point in the lifespan (Matza, 2004). An additional methodological consideration is that of whose perspective to use, i.e. the child or their parent's (Rosenbaum & Saigal, 1996). Proxy

response and age related considerations are discussed further in the following sections.

With these issues in mind current literature makes certain, sometimes tentative, recommendations for child QoL instruments. Items on any questionnaire should be easy for the respondent to comprehend both in relation to the content of the question and also how to score each answer. In addition, the language used should be suitable for the age group being investigated (Erling, 1999), and this can be assessed using recognised standards such as the Flesch readability formula, as seen in table 2.2 (Flesch, 1948). There is, however, still much work to be done in relation to mode of administration, particularly in younger children. Alternatives to the traditional use of paper and pencil measures need exploring further, as does investigation of which mode is most appropriate for specific age groups (De Civita *et al.*, 2005). Previous suggestions have included the use of pictures, videos, computers and puppets (Jenney, 1998, Eiser and Morse, 2001a), and these are discussed further in the following chapter.

Flesch Reading Ease Score	206.835 – (1.015 X ASL) – (84.6 X ASW)
Flesch-Kincaid Grade Level Score	(.39 X ASL) + (11.8 X ASW) -15.59

ASL = average sentence length (number of words divided by number of sentences)
ASW = average number of syllables per word (number of syllables divided by number of words)

Table 2.2: Formulae for Flesch Readability Scores

(2-5-ii) Proxy response in child measurement: With regard to who is the most appropriate respondent in assessing child QoL, there are a number of factors that require consideration. One such factor relates to developmental stage, with age 9-10 regarded as the lower limit for subjective concepts such as self-esteem and behaviour (Landgraf & Abetz, 1996). However, as Erling (1999) points out, it is important, where practical, to use the children's own report when measuring their QoL, and not proxy report by adults such as parents, teachers or doctors. It is the child's perspective that is important and they may acknowledge very different aspects as being important to them than adults do. This, however, can be difficult to achieve with very young children or those who are physically ill or disabled, and in such cases parental proxy report may be required (Varni, *et al.*, 2005).

Evidence from the adult literature suggests clinicians are poor at assessing HRQoL (Wilson *et al.*, 2000). Specifically with regard to the literature on children and adolescents, Meade *et al.* (2001) report that whilst 'negative life events are associated with poorer health in children, regardless of who reports the health', child and parental ratings are fundamentally different, and parental reports can also be influenced by the child's ability in identification and communication of their feelings. More recent research suggests that it is not interpretation of items that differs in children and their parents, but rather the response styles and reasoning methods of the two groups. Children appear to employ a more extreme form of response choice (i.e. the highest or lowest response option), and to base their response on a single example (Davis *et al.*, 2007; Chambers & Johnston, 2002).

Verrips *et al.* (2000) suggest that the accuracy of proxy reports might be domain specific, and that parents may be better judges of physical functioning and symptoms than they are of more covert dimensions such as pain and emotional and social functioning. These findings are broadly supported by Eiser and Morse (2001c) in their review of research that explores the relationship between child and proxy ratings. The authors of this work also report that the accuracy of parental ratings can be influenced by demographic variables such as gender, age of the child and health status. Theunissen *et al.* (1998) studied ratings of a large cohort of 8-11 year olds and their parents, and concluded that whilst parental ratings may be adequate at group level, 'large differences can exist in proxy agreement at the individual child-parent level'. In summary, whilst it is clear that both child and proxy ratings have a role in QoL assessment (Gerharz *et al.*, 2003), wherever possible measurement should be achieved by self-report (Ravens-Sieberer *et al.,* 2006).

(2-5-iii) Age specific considerations: Age is a fundamental consideration in the investigation of QoL of children and adolescents. For example, researchers have a delicate balancing act when exploring 'role' expectations. Landgraf and Abetz (1996) demonstrate this through their comparison of mid (age 14-16) and early (age 11-13) adolescents. The 'role' of the former may include that of a part time job, as well as activities with friends and attending school. For early adolescents just some 2 years younger questions relating to 'work' would be inappropriate. This, the authors state, highlights that 'applicability at both the item level and concept level needs to be demonstrated empirically across developmentally appropriate age groups'.

Practical considerations also need to be considered wherever possible. The length of instruments requires consideration, with older children generally able to complete longer questionnaires as a result of their increased attention span (Matza *et al.*, 2004). Children's degree of independence during administration is also relevant. Erling (1999) refers to the need for participants to be allowed undisturbed time alone in which to complete their questionnaires, and also the need to respect young people's integrity, just as one would with adult participants. Younger participants, however, may require assistance with reading and completing questionnaires, and also with remaining focused throughout the administration procedure (Matza, *et al.*, 2004).

(2-5-iv) Child & adolescent specific measures: Numerous measures have been developed for use with children and adolescents, and a number of reviews of instruments make recommendations based on many of the issues discussed. For example Eiser and Morse (2001b) identify a limited pool of measures, both disease specific and generic, which they regard as suitable for current use on the basis of fulfilling 'very basic psychometric criteria' of reliability and validity. Hence the authors recommend the use of the generic Child Health Questionnaire (Landgraf *et al*, 1998), the PedsQL (Varni *et al.*, 1999) and the Health Utilities Index (Feeny *et al.*, 1998), which adopts a HRQoL approach. The Paediatric Cancer Quality of Life Inventory (Varni *et al.*, 1998) and the Paediatric Asthma Quality of Life Questionnaire (Juniper *et al.*, 1996) are the sole disease specific instruments endorsed.

Similarly, Harding (2001) in her review of eight measures makes reference to the importance of strong psychometric properties, and notes that instruments 'refined to cover a small number of domains have the best psychometric properties'. In particular the author highlights three instruments; How are You? (HAY; Bruil *et al.*, 1996), KINDL (Ravens-Sieberer & Bullinger, 1998), and the Child Health and Illness Profile – Adolescent Edition (Riley *et al.*, 1998). The PedsQL and HAY are further endorsed by Wallander *et al.* (2001) in their review of six generic measures.

A more recent review by Cremeens *et al.* (2006) continues to question the psychometric properties of QoL measures for children. Specifically the authors call for greater evidence of reliability and sensitivity to change, as well as an assessment of the impact of different presentation formats on these properties. A further review by Ravens-Sieberer *et al.* (2006) suggests that whilst many instruments for young people do demonstrate acceptable reliability and validity, sensitivity to change has

Greater attention is now being paid to these issues by a number of researchers (i.e. Petersen *et al.*, 2005; Baars *et al.*, 2005), with a focus on developmentally appropriate instruments that incorporate age-specific questions and response formats. The next phase in this process is to identify developmental norms for children experiencing challenges to their health, in order to 'provide a guide to normative expectations for children living with illness at differing ages' (De Civita *et al.*, 2005). The most significant current weakness, however, lies in the ability to make valid cross-cultural comparisons in young people's HR-QoL (Ravens-Sieberer, *et al.,* 2006). Greater consideration of different cultural perspectives when constructing instruments to allow for international comparisons remains a goal for future research in this field.

(2-7) Chapter summary: This chapter has outlined the concept of QoL and its measurement, and also highlighted considerations specific to children and adolescents. A brief discussion has also been undertaken of current conceptual and methodological issues relating to QoL measurement in young people. Chapter 3 includes a more detailed discussion of a number of the issues raised in this chapter, particularly those relating to the testing of psychometric properties and alternative modes of administration when measuring QoL.

Chapter 3: The Design and Administration of Survey Instruments: An Overview

(3-1) Background: The last 20 years has seen dramatic changes in the field of survey methodology. For example, the pre-testing of instruments has been greatly influenced by the application of cognitive science (Presser *et al.*, 2004a), and instrument administration is increasingly influenced by modern technology such as computers and the Internet. Developments apart, the underlying principles of traditional psychometrics still remain the standard by which questionnaires are judged, although modern techniques such as item response theory have evolved as an alternative to classical test theory. The Rasch model of item response theory (Rasch, 1993) has been of particular significance (Bhakta *et al.*, 2005), and some investigators are now using both traditional and modern methods in conjunction with one another and comparing their relative strengths and weaknesses (i.e. Prieto *et al.*, 2003).

(3-1-i) Aims of chapter: The aim of this chapter is to provide an overview of methods employed in the construction, pre-testing, and administration of scientifically sound survey instruments. Specifically the chapter aims to:

- Evaluate methods employed in generating items for survey instruments
- Evaluate methods employed in pretesting survey instruments
- Discuss the testing of psychometric properties in order to demonstrate how this influenced the choice of measures in later experimental chapters
- Evaluate methods employed in the administration of survey instruments

In doing so both traditional and modern methods are discussed as a means of conveying the vast array of methods employed, and also in recognition of the fact that few methods are used in isolation. Specific attention is given to those methods used and reported in the following two chapters, which report the further development and pre-testing of the PIIS, and it's subsequent psychometric evaluation.

(3-2) Item Generation: A variety of procedures can be utilised in generating questions in the development of a new measure. The following section briefly discusses five of the most common of these; key informant interviews, focus groups, literature review, clinical observation and expert opinion.

(3-2-i) ***Key Informant Interviews (KIIs)***: KIIs refer to in-depth interviews with individuals on the basis of their unique situation and knowledge. As such, participants are not randomly selected; rather they are recruited on the basis of their experience, and willingness to engage, with the research area (Johnson, 1990). Interviews can be structured or semi-structured, with the latter considered most appropriate where little is known about the field under investigation (Streiner & Norman, 2000). The two most common methods utilised in conducting KIIs are telephone and face to face interviews, the latter being the most frequently employed. Although more time intensive the face to face format allow for 'a free exchange of ideas, and lends itself to asking more complex questions and getting more detailed responses' (UCLA Centre for Health Policy Research). No rigid guidelines exist on the number of KIIs to conduct, rather it is generally accepted to 'sample to redundancy', i.e. continue to interview until no new items or themes are being generated (Streiner & Norman, 2000).

As with all qualitative research methods care is required in their execution in order to protect their validity. On a very basic level, the interviewer requires sufficient knowledge themselves of the area under investigation to be able to recognise when a particular response requires additional investigation or 'probing' (Sofaer, 2002). A specific technique employed in enhancement of validity is so called 'member checking'. The process can involve one or two phases as a means of ensuring that data truly represents the views of the respondent. Firstly the interviewer will summarise or paraphrase the responses of the participant during the interview as a means of confirming their interpretation is correct. This can be followed by presenting a report of the KII to interviewees for critical evaluation of the reported data (Kuzel & Like, 1991).

A further method for protecting validity is the process of triangulation, which involves the use of multiple methods and data sources as a means of gaining a thorough understanding of the target of investigation. Such a process is now regularly employed, and KIIS are increasingly used in conjunction with other methods, such as literature review, focus groups and expert review in questionnaire development and validation (i.e., Kim *et al.*, 2006; Hsu *et al.*, 2006; Robling *et al.*, 2002).

(3-2-ii) ***Focus Groups***: Originally developed as a market research tool to assess consumer responses, the use of focus groups in generating themes for health measurement tools has accelerated considerably in recent years (Sofaer, 2002). As

discussed in chapter 2, it is now recognised that although, for example, clinicians may be the best observers of clinical manifestations, individual themselves are the best at reporting the more subjective elements (Wilson *et al.*, 2000). Focus groups address this issue in being made up of participants representative of those whose opinions would be elicited by the questionnaire (Streiner & Norman, 2000), and have been conducted successfully with children as young as eight years old (Detmar *et al.*, 2002).

Groups are generally made up of 6-12 members, and directed by an interviewer / facilitator (Willms & Johnson, 1993; Bowling, 2000) who guides participants through the process to talk spontaneously about themes relevant to the field of investigation. Sessions are tape-recorded with observational notes also taken by some investigators. There is significant disparity in recommended guidelines for the number of focus groups to conduct. For example, Streiner & Norman (2000) suggest no more than two to three, whilst Bowling (2000) suggests from six to twenty, with groups lasting between one to two hours.

As with KIIs, the success and validity of the process relies largely on the skills of the interviewer (Sofaer, 2002), and as Bowling (2000) states, in 'creating a relaxed atmosphere, leading group discussions and handling conflict, as well as drawing out passive participants'. The success of the technique also depends largely on the focus of investigation; the nature of the group process might inhibit free discussion of particularly sensitive issues, and in such cases KIIs are considered more appropriate (UCLA Centre for Health Policy Research).

(3-2-iii) ***Literature Review***: The use of previous research findings in the development of measurement scales is widely employed, and particularly at the outset of the development process as a means of identifying an initial pool of items or concepts (i.e. Webb *et al.*, 2002; Rouland *et al.*, 2002; Badia *et al.*, 2005; Badia *et al.*, 2007). The availability of electronic databases such as Web of Science, Psychlit, Medline, Embase and the Cochrane Library has greatly aided this process. Not all databases incorporate articles from specific fields, and hand searches of relevant journals are recommended to account for this, as well as discrepancies in database indexing (Bowling, 2000).

The key advantage of basing measures on previous research is that, as items are based on empirical findings, they are characteristic of the group of people under

investigation. If using such an empirical approach when investigating a field where no previous research has been completed, new research may be required in order to facilitate the development of an appropriate scale (Streiner & Norman, 2000). A key limitation of reviewing literature using electronic databases is that non-significant research findings are rarely published, and remain hidden in what is sometimes labelled the 'grey literature'. An exhaustive literature review therefore requires assessment of both published and unpublished material, the latter only usually accessible from experts within a given field and attendance at relevant conferences (Bowling, 2000).

As McDowell & Newell (1996) make clear, the sole use of empirical data to develop questionnaires is now less prevalent, and a theoretical approach is increasingly employed. Developing scales in relation to established theory has the advantage of results explaining, rather than just describing, an individual's responses. The field of QoL is just one such example of where established theory is now prominent in the development of measures (i.e. Whalley *et al.*, 2004; Chen *et al.*, 2004). The process of literature review when constructing new questionnaires must therefore take account of both empirical and theoretical material.

(3-2-iv) ***Clinical Observation***: Streiner & Norman (2000) state that clinical observation and experience are a particularly prolific method of item generation and arguably one that 'precedes theory, research or expert opinion'. The authors do however go on to point out some disadvantages of relying solely on observation. They point to the fact that clinicians might be wrong in their observations, and that due to a small number of patients or 'narrow perspective imposed by a particular model' may be unaware of other important factors.

A number of well established instruments have been developed either partially or wholly on the basis of clinical observation, including the Alzheimer's Disease Assessment Scale (Rosen & Mohs, 1983), the Pain and Distress Scale (Zung, 1983), and the Hamilton Rating Scale for Depression (Hamilton, 1960). The most prominent, however, is the widely adopted Beck Depression Inventory (BDI; Beck, 1961), which was based on observations of psychotherapeutic consultations, as opposed to established theoretical positions of depression. A significant body of literature has evolved relating to the sound reliability (i.e. Beck, *et al.*, 1988; Gallagher, 1986; Gould, 1982) and validity (i.e. Oliver & Simmons, 1984; Moran & Lambert, 1983) of the instrument, although a number of authors have reported evidence of social

desirability response bias (Beck, *et al.*, 1988), and also in difficulties with the 4-point response scale (Kearns, *et al.* 1982). These issues aside the BDI is widely used in both clinical and non-clinical samples, and demonstrates the significant input clinical observation can have in instrument development.

McDowell & Newell (1996) point out that the development of instruments based solely on clinical observation is now less prevalent with the use of a number of the techniques discussed in this section regarded as the norm. That is not to say the input of clinicians is now redundant. As the authors summarise in their discussion of the theoretical and technical foundations of health measurement:

'we should be careful not to forget the importance of sound clinical insight into the nature of the condition being measured; the ideal is to use statistically correct procedures to refine an instrument whose content is based on clinical wisdom, and common sense' (p.42).

(3-2-v) ***Expert Opinion / Review***: A recognised component of instrument development and pre-testing is to seek the input of 'experts' in the field to which the questionnaire relates (Tourangeau *et al.*, 2000). The clearest single advantage to using expert opinion is that the participants involved are generally the most up to date in their given field. In assembling a panel of experts, researchers have access to the most forward thinking in a given area. The technique has also been shown as highly cost-effective in comparison to other methods employed in the development of survey instruments (Presser & Blair, 1994).

Caution, is necessary with expert panels whether employed at the item generation or pre-test phase. In the former, should the expert group reflect a degree of bias, i.e. not express a full range of opinions or viewpoints, items that are generated may not sufficiently cover the area under investigation (Streiner & Norman, 2000). There is conflicting evidence as to the validity of expert panels at the pre-test stage. A study by Presser & Blair (1994) concluded that the technique is particularly effective in identifying issues surrounding comprehension of items and potential analysis difficulties. In stark contrast, van der Zouwen & Smit (2004) found little concurrence between expert panel judgements regarding problematic items and subsequent item performance.

As with KIIs and focus groups, current literature provides little guidance on the number of experts to consult. Streiner & Norman (2000) suggest a figure of approximately three to ten experts, and this figure seems broadly adopted in many studies that adopt the procedure (i.e. Cheng *et al.*, 2007; Badia *et al.*, 2005; van der Zouwen & Smit, 2004), although some, for example Frost *et al.* (1998) who consulted 37 'professionals and support workers', employ considerably more. In addition, there are no detailed criteria on how expert panels should be conducted, and subsequent opinions analysed (Streiner & Norman, 2000). Some take the form of focus groups, (i.e. Spiegel *et al*, 2007), others interviews (i.e. Hobart *et al.*, 2001), and others incorporate postal methods (i.e. van der Molen *et al*, 2003).

(3-2-vi) ***Summary***: As a significant body of literature makes clear none of the processes described above is mutually exclusive. Rather 'a scale may consist of items derived from some or all of these sources. Indeed it would be unusual to find any questionnaire derived from only one of them' (Norman & Streiner, 2000). A weakness of the techniques discussed is the lack of apparent guidance in there execution, although there is general consensus that the employment of multiple methods in questionnaire development has lead to significant advances in the validity of survey measures (Sofaer, 2002; McDowell & Newell, 1996).

(3-3) Pre-testing of Instruments: A fundamental process in the development of any measurement tool is to pre-test the instrument in question. A number of established procedures are employed including card sorting, vignettes, expert / peer review, focus groups, respondent debriefing, and cognitive interviews, the latter being by far the most commonly used (Tourangeau *et al.*, 2000). Such techniques have essentially replaced the traditional field pre-test due to a number of limitations. Firstly, the field pre-test focuses on the data collection process in its entirety, and not just on a single instrument, hence diffusing attention from the questionnaire. Secondly, the field pre-test only exposes directly observable problems, and fails to reveal more subtle, covert problems that can arise from the question-answer process. Lastly field pre-tests are almost always conducted at the end stage of the development process, and provide limited time for any significant changes to be made (Willis, 1994). As the most widely used technique at present, and that used in the further development of the PIIS, there follows a detailed account of cognitive interviewing, followed by a brief explanation of supplementary techniques used in the pretesting of survey instruments.

(3-3-i) Cognitive Interviewing: Cognitive interviewing techniques emerged in the 1980's (Willis, 1994) and are now commonly reported with both adults (e.g. Shaw *et al.*, 2001) and children (e.g. Rebok *et al.,* 2001). The underlying premise behind the use of such a procedure is that it is vital to understand the mental processes employed by study participants in formulating their responses. Gaining such an understanding 'ensures that items are performing in the manner intended' (Frank *et al.,* 2001). This highlights an even more fundamental principal in developing measurement tools; the importance of both item content and item clarity, and that 'no amount of sophisticated psychometrics can compensate for deficiencies in *what* and *how* questions are asked' (Shaw *et al.*, 2001).

Cognitive process theory suggests that individuals undertake four processes when responding to questions (Warnecke *et al.*, 1997) and these can be used as a framework for the interpretation and assessment of cognitive interviews (Friedenreich *et al.,* 1998; Frank *et al.,* 2001). The four processes comprise of:

- *Item interpretation:* does the respondent understand the question?
- *Information retrieval:* can respondents recall the information being sought?
- *Judgment formation:* what strategies are used by respondents when estimating time spent on various activities, and are these estimates accurate?
- *Response editing*: do respondents give unbiased, accurate responses, or are they influenced by social desirability?

In briefly discussing each of these processes and their relevance to cognitive interviewing, it should first be highlighted that 'consistent *item interpretation* is fundamental to the accuracy of data collected and interpretations based on those data' (Frank *et al.,* 2001). Assessment of item interpretation is therefore a central theme running through the vast majority of methodological techniques employed, although specific ways in which this is applied differs from study to study (e.g. Frank *et al.,* 2001; Shaw *et al.,* 2001; Friedenreich *et al.,* 1998).

Cognitive process theory suggests that in the second task of *information retrieval* commonly occurring events are likely to be recalled as generalised schemas, rather than specific episodic events. This might have particular relevance to time referents employed on questionnaires, although there is clearly a balance to be struck. If the time referent is too short in attempts to gain discrete episodic recall, respondents may ignore instructions to answer within a specific time referent, as they may not have experienced the issue in question within that time period. This can in turn lead

to their forming responses based over a longer period of time and result in more generalised schema recall (Frank *et al.,* 2001).

The third task of *judgment formation* may also have relevance to time referents. Cognitive process theory postulates that episodic recall is less sensitive to cultural bias than is generalised schema recall. This being so Frank *et al.* (2001) suggest encouraging respondents 'to focus on specific events in the prior week' and thereby 'improve data quality by minimising the potential bias and distortion introduced by cultural influences on response.

Finally, the fourth task of *response editing* can be highly influenced by perceived social desirability, and result in respondents answering in a way they assume is expected of them. As such this can have major implications for validity, with the greater the degree of response editing the greater the bias introduced. Warnecke *et al.*, (1997) suggest that the likelihood of response editing is enhanced where there are cultural differences between respondent and interviewer. This might have wider implications dependent on specific research populations and environments. For example Frank *et al.,* (2001) cite the disparity in ages between their interviewers and respondents as potentially influential, but it seems reasonable to suggest that this might extend to factors such as gender, particularly when measuring sensitive or potentially embarrassing issues.

(3-3-i-a) Cognitive Interviewing Methods: Two main cognitive interview methods are highlighted by Willis (1994); 'think aloud' interviewing, and the probing technique. When employing the 'think aloud' technique, participants are asked to verbalise their thought processes whilst answering the question, with the interviewer injecting little else to the process other than to instruct 'tell me what you're thinking'. The main advantages of this method are the lack of bias imposed by the interviewer on the respondent, and also the relatively little burden placed on the interviewer, thereby maximising their time to concentrate and record what is being reported by the respondent. A further advantage is that with such an open, unstructured format the participant receives minimal guidance, and the emergence of unanticipated response patterns is greatly enhanced.

A number of disadvantages, however, do exist. Firstly the technique of thinking aloud is somewhat unnatural and this artificial nature of the task can cause difficulties for some participants, who may therefore require a deal of training prior to interview.

Even after training it is apparent that some participants fail to master the technique, and simply answer the question being asked. Secondly, due to the intrinsic nature of the task, and with so little input from the interviewer, participant burden is naturally high. Third, with so little structure the tendency to go 'off track' is high, although as previously mentioned this can be viewed as an advantage in certain instances. Lastly, there may well be a degree of bias introduced by asking participants to place a greater level of mental effort when answering than they would do under normal survey conditions (Willis, 1994).

The probing technique has similar pros and cons, but is the method recommended by the Questionnaire Design Research Laboratory, National Centre for Health Statistics, USA. The major advantage over the 'think aloud' technique is that the interviewer maintains full control over the interview, and this naturally places fewer burdens on the respondent. Alternatively, critics point to the potential to 'lead' respondents by the use of probes, and also that their use can make the situation very different to the normal survey process (Willis, 1994).

(3-3-ii) ***Card sorting techniques***: Card sorts involve participants sorting statements, concepts or objects into piles by similarity as a means of identifying underlying dimensions or constructs of the area under investigation. These are then analysed using cluster analysis, an exploratory statistical tool designed to sort variables into pools on the basis of similarity, as a means of identifying the cognitive structures implicated in participants similarity ratings (Torangeau *et al.*, 2000). The technique has previously been incorporated in both the development and improvement of scales (i.e. Brewer *et al.*, 1989), but is now rarely used, having been superseded by the previously discussed cognitive interviewing techniques.

(3-3-iii) ***Vignettes***: Vignettes, hypothetical situations presented to participants for evaluation, have long been used in psychological research. For example Piaget used such a technique when studying the development of moral reasoning in children. The use of vignettes in the design and evaluation of survey instruments is more recent, the first study being reported in 1986 (Biderman *et al.*). Although questions still remain over the validity of the procedure, Martin (2004) identifies four areas where vignettes are particularly useful, namely exploring of conceptual domains, their interpretation, identifying the dimensions of concepts, and identifying wording problems. The technique is regarded as particularly useful when exploring particularly sensitive issues due to their hypothetical nature, and hence participants

being removed from their own situation. As with card sorts, the technique is less utilised than previously, although is still regarded as useful in the development of instruments for children and adolescents (Stanford *et al.*, 2006; Cook *et al.*, 2001).

(3-3-iv) ***Focus groups***: As discussed previously, focus groups are initially used as a means of generating themes in the development of a measurement tool, but are often engaged again in the pre-test phase when items have been written, in order to determine that they are clear, relevant and unambiguous. As Streiner & Norman (2000) make clear, focus groups at the pre-test phase have greater focus that at the item generation phase 'since there is a strong externally generated agenda; discussing the items themselves'.

(3-3-v) ***Response latency***: Reaction time measures have traditionally been used to study the organisation of particular memory domains (e.g. Collins & Quillian, 1969) or the cognitive processes employed when attending to specific tasks (e.g. Sternberg, 1969). More recent research has used response latency to assess the strength of attitudes (Bassili & Scott, 1996), and as a guide to problem items in survey instruments. The technique has so far provided inconclusive results with regard to the latter. Draisma and Dijkstra (2004) suggest that slower reaction times indicate uncertainty on the part of the respondent, resulting in inaccurate answers. Shaeffer and Dykema (2004), and Martin (2004) have shown that no such relationship exists. Interpretation of response latency is clearly not straightforward, and requires further investigation as to when respondent uncertainty is a useful predictor of response error. As Presser (2004) points out it may well be that longer reaction times are a reflection of careful processing rather than a high degree of difficulty.

(3-3-vi) ***Interaction / behaviour coding***: The coding of interactions between interviewers and respondents has also been used as a tool to identify potentially problematic questions (Fowler 1992). The number of participants asking for clarification, or the giving of unacceptable answers provides a guide as to how problematic a question is, and if it is being interpreted as intended (Torangeau *et al.*, 2000). The validity of the technique is unclear as different researchers employ a range of criterion in what constitutes a problematic item in their coding of behaviours (van der Zouwen & Smit, 2004). Some use the percentage of correctly answered questions (i.e. Hess *et al.*, 1999), others the percentage of respondent problems (i.e. Oksenberg *et al.*, 1991), and others the percentage of questions 'skipped' (i.e. Comijs *et al*, 2000).

(3-3-vii) ***Respondent debriefing***: Respondent debriefing is conducted following a survey interview or administration of a survey instrument, and involves a second interview containing a series of follow-up questions. Such questions, or probes as used in cognitive interviews, can be used to assess item interpretation, the experience of the respondent during the survey (i.e. subjective thoughts or reactions), and the identification of missed or misreported information (Martin, 2004). As with a number of the techniques discussed so far in this chapter the number of participants to employ in respondent debriefing is unclear, some using sample sizes of 20 participants, others in excess of 100 (Willimack *et al.,* 2004). There is also diversity in the manner in which debriefs are conducted. Willimack *et a*l. (2004) point out that most are conducted either face-to-face or by telephone, although some have employed a self-administered debrief (DeMaio & Jenkins, 1991).

(3-4) The Testing of Psychometric Properties: The development of scientifically sound questionnaires is underpinned by long-standing psychometric principles. Any measure should be reliable, valid and responsive or, as Thompson (2000) translates, 'must be free from random error, measure what it purports to measure, and be sensitive to change'. There follows a summary of these principles, which were used to guide the selection of instruments selected in chapter 5, and also the psychometric evaluation of the revised Parental Illness Impact Scale.

(3-4-i) Validity:

(3-4-i-a) ***Face Validity***: The most basic form of validity, a largely subjective concept based on researcher's opinions as to whether questions appear at face value to measure what they are intended to. Face validity is subsequently confirmed, or otherwise by assessment of content validity as discussed in the following sub-section (Bowling, 2000).

(3-4-i-b) ***Content Validity***: Often confused with face validity, and again a subjective concept, content validity focuses on the extent to which an instrument adequately probes the various aspects of the area it's designed to measure. This is achieved in a more systematic way than face validity, often through the opinion of focus groups, and or expert panels (De Civita *et al.*, 2005; Bowling, 2000) as discussed in sections 3-2-ii and 3-2-v.

(3-4-i-c) ***Construct Validity***: The degree to which an instrument questions capture the hypothetical quality or trait it is designed to measure. This is usually established using factor or principal components analysis. The two techniques are similar, and

differ only in their observation of variance. In factor analysis only shared variance is analysed, and in principal components analysis all observed variance is analysed (Tabachnick & Fidell, 2000). A group of items, or factor, is usually retained if it demonstrates an Eigenvalue in excess of 1.0 (Hutcheson & Sofroninou, 1999). Factor loadings indicate the degree to which an item is a true measure of the factor in question, with loadings >.71 regarded as excellent, > .63 very good, >.55 good, >.45 fair, and >.32 as weak (Kline, 1994).

(3-4-i-d) ***Concurrent Validity***: The extent to which an instrument correlates with other instruments designed and validated to measure similar or related constructs. Correlations between instruments is generally seen at between 0.40 and 0.60, and correlations at the 0.60 level are regarded as representing 'an extremely strong association' (McDowell & Newell, 1996).

(3-4-i-e) ***Discriminant Validity***: The opposite of concurrent validity, discriminant validity relates to the degree to which an instrument does not correlate with dissimilar unrelated constructs. There are no specified criteria for what constitutes sound discriminant validity, although some have interpreted a lack of statistical significance between two measures as sufficient evidence (i.e. Gotay & Pagano, 2007).

(3-4-i-f) ***Predictive Validity***: The extent to which scores on an instrument reflect or are predictive of actual performance, and particularly important in the assessment of personality, where tests are used as the basis of job selection. Predictive validity is rarely assessed in clinical studies due to the length of investigation required and methodological problems. For example, during the course of a given study those individuals at highest risk might be subject to interventions that may change the predicted outcome, and therefore incorrectly render the instrument as showing poor predictive validity (McDowell & Newell, 1996).

(3-4-ii) Reliability

(3-4-ii-a) ***Internal Consistency***: Measured using Cronbach's alpha coefficient, this provides a measure of inter-item consistency within a scale by describing how well a group of items focuses on a single idea or construct. The widely agreed minimum standard for internal consistency is an alpha value of >0.70 (Scientific Advisory Committee of the Medical Outcomes Trust, 2002), although some have suggested >0.50 is sufficient (Helmstater, 1964). Alpha coefficients can be calculated for the internal consistency of subscales within an instrument, and for the instrument as a whole.

(3-4-ii-b) ***Test-Retest Reliability***: The extent to which an instrument provides the same results on the same individual on two or more occasions, presuming that there

has been no change in the status of the construct being measured. For nominal and ordinal data Kappa coefficients are calculated, with Pearson correlation coefficients used for interval level data (Bowling 2000). Kappa values greater than 0.6 are regarded as 'substantial', and above 0.8 as 'almost perfect' (McDowell & Newell, 1996). Pearson coefficients above 0.7 are considered as showing sound reliability (Fitzpatrick *et al.*, 1998), although correlations above 0.6 show substantial agreement (Andrews, 1976).

(3-4-ii-c) ***Inter-Rater Reliability***: The degree to which different observers agree in their ratings. As above the level of agreement is assessed using either Kappa or Pearson correlations. Results above 0.60 are considered to indicate sound reliability (Fleiss, 1981).

(3-4-ii-d) ***Intra-Rater Reliability***: The degree to which the same observer agrees in their ratings at different assessment periods. Correlations of above 0.80 are an indication of high reliability (Bowling, 2000).

(3-4-iii) ***Sensitivity to change*****:** Sensitivity or 'responsiveness' refers to the detection of significant change, and is particularly important where treatments are associated with small but important changes. Statistical analysis of such changes can incorporate a number of procedures, including paired t-tests, and analysis of variance where control groups are employed (De Civita *et al.*, 2005)

(3-5) Instrument Administration: There is now a vast array of methods incorporated in the administration of survey instruments, and this is increasingly being influenced by the introduction of modern technology. The following section discusses five modes of administration. Firstly the traditional methods of interviewer, telephone and postal administration are presented. This is followed by two relatively new methods; electronic and internet administration.

(3-5-i) ***Interviewer administration***: Until the 1970's face-to face surveys were the sole source of survey data widely accepted to be scientifically reliable. Increased labour costs and advances in data collection via postal and telephone methods (discussed below) have largely discredited this view (Salant & Dillman, 1994). A clear disadvantage of interviewer administration is the high cost incurred, especially where large sample sizes are involved. There are, however many benefits to this mode of administration and none more so than that the interviewer has personnel contact with the participant. Questions can therefore be clarified, and the experimenter can also adapt and be certain of the environment in which the respondent is answering.

Interviewer presence also facilitates the asking, and clarification if required, of more complex questions that respondents may find difficult or confusing over the telephone or by mail.

(3-5-ii) ***Telephone administration***: This is cheaper than face-to-face interviews, due to the decrease in costs incurred primarily through travelling. However, as Bowling (2000) points out, costs are not necessarily small. Estimates suggest that 50% of calls are either not answered, find the line engaged, or are met by an answering machine. This on average necessitates three call backs for each number dialled. Telephone surveys can also exclude participants from low socio-economic status background who do not have a phone (Salant & Dillman, 1994), thus leading to biased samples. Another disadvantage is the propensity for non-response on sensitive issues (Wells *et al.*, 1988). In brief telephone administration is most effective with short, non-sensitive questionnaires (Bowling, 2000), and there is limited evidence that respondents prefer face-to-face surveys to those conducted by telephone (Groves 1979).

(3-5-iii) ***Postal administration***: This is by far the most cost-effective mode of administration, but a number of limitations should be noted. Fundamentally the investigator has no influence over the environment in which the respondent completes the questionnaire. In addition it is necessary to ensure contact via phone and email is available for issues of clarification should these arise. Another limitation is the propensity for low response rates that can subsequently lead to non-representative samples. The sending of reminders to non-responders, usually 1-4 weeks after administration, is standard procedure in postal surveys (Salant & Dillman, 1994; Bowling, 2000). A recent Cochrane review (Edwards *et al.*, 2001) focuses on strategies likely to influence response rates in postal administration. Among those strategies most likely to increase response the authors site 'user-friendly', short questionnaires, follow-up of non-responders, the use of first class postage, stamped rather than franked, and coloured rather than black ink. Both monetary and non-monetary (i.e. key-ring, final report) incentives have been shown to increase response. Of those factors most likely to decrease response Edwards *et al* point to sensitive questions, questionnaires starting with very general questions at the beginning, and also giving respondents the option of not participating.

(3-5-iv) ***Electronic Administration***: For a relatively new mode of administration, a small but important body of literature has emerged on computer-assisted

approaches. Major disadvantages of the traditional pen and paper techniques are the subsequent data entry and summation of scores. Computer administration can overcome this with simple programmes to calculate scores (Drummond *et al.*, 1995). The technique can also dramatically reduce the occurrence of missing data, for example in obtaining responses to sensitive questions (Pouwer *et al.*, 1998). Other advantages include question branching and the facility to produce automatic reports (Boyes *et al.,* 2002). Additionally Litaker (2003) states that 'controlling information about individual questions and use of standardised instructions may lessen concerns about interviewer bias'. There are, however, some important questions to be answered in relation to electronic administration and particularly with regard to changes in psychometric properties and effects on reliability when traditional pen and paper instruments are merely reproduced in electronic format (Boyes *et al.*, 2002; Litaker, 2003). Some studies report a high degree of concurrence between pen and paper and electronic methods (e.g. Pouwer et al, 1998; Ravens-Sieberer et al 2000), others less so (e.g. Boyes *et al.*, 2002). The question of ease of use or whether respondents actually prefer computer administration has also been assessed. Buxton *et al.* (1998) reported 98% of participants using a touch-screen video monitor as 'very easy', whilst Drummond *et al.* (1995) report 57% of their participants preferring electronic administration, 13% the traditional pen and paper method, with 30% expressing no clear preference. Children also report a preference for computer administration over pen and paper (Ravens-Sieberer *et al.*, 2000). It may well be that future developments allow for groups traditionally excluded from pen and paper to be included, such as those with poor levels of literacy. Hahn *et al.* (2002) report the successful use of a 'talking touchscreen' with low and high literacy patients, with over 60% of both groups expressing a preference for this over interviewer administration.

(3-5-v) ***Internet administration***: There are clear similarities between electronic and internet administration, but a small number of studies have focused specifically on the latter. A major advantage of administering via the Internet is the potential for large scale participation in research studies and clinical trials, as well as the 'development of web-based decision-support applications for patients' (Lenert, 2000). A study by Baylis *et al.* (2003) administering the Headache Impact Test (HIT) via the internet concluded that web-based testing actually motivated patients to pursue treatment and engage with service providers with regard to their headaches. Another recent study by Bush *et al.* (2005) used web-based administration for daily and monthly symptom and QoL assessment in discharged patients following haematopoietic stem

cell transplantation. The authors conclude that this frequent mode of assessment shows high feasibility, patient compliance and satisfaction.

Current limitations exist however, and, as discussed previously, none more so than in the potential impact on traditionally validated instruments' psychometric properties. Whilst Lenert (2000) has demonstrated strong reliability and internal consistency in measurements of utilities in an instrument designed specifically for web-based administration, both she and others (e.g. Litaker, 2003) underline the need to compare traditionally developed measures with those designed or adapted for use on the internet and computer administration. Assessment of the affects of factors such as survey environment, differing web and computer-based interfaces need to be taken into consideration. As with computer administration, Internet administration has been shown to be preferable over traditional survey methods in a group of adolescents aged 13-17 (Mangunkusumo *et al.*, 2005).

(3-6) Proxy Versus Self-Report: Proxy response is most widely used in physically and cognitively impaired patients, the elderly, and child populations, the latter having been discussed in chapter 2. The use of proxy measures for physically and cognitively impaired patients, such as those following stroke, is crucial in that such patients may experience difficulty in responding to survey questions (Dorman *et al.*, 1997). In incorporating proxy respondents samples sizes can be increased and be more representative (McRae *et al.*, 2002; Buck *et al.*, 2000) as well as result in higher response rates (Corder *et al.*, 1996). The problem remains as to how reliable proxy response is and the degree of bias therein. Evidence from the research literature suggests certain domains are more accurately reported by proxies than are others. Dorman *et al.* (1997), report accurate and non-biased proxy ratings for stroke patients in domains of mobility and self-care, but poor in those of psychological functioning. Also the relationship of the proxy appears important, with, for example, physicians having been noted as relatively poor in judging subjective areas of QoL in cancer patients, with spouses reporting significantly closer ratings (Wilson *et al.*, 2000). Some evidence also suggests that level of caregiver burden affects proxy ratings of spouses / carers in the elderly, particularly with regard to functional status (Long *et al.,* 1998). The overwhelming message from the literature is that where possible the individual should be the respondent in preference to a proxy (e.g. Wilson *et al.*, 2000).

(3-7) Generic versus Disease-Specific: The question of whether to administer generic or disease specific instruments has not been well-addressed in the literature (Streiner & Norman, 2000). As stated by Kirkley & Griffin (2003) both have clear advantages and disadvantages. Generic instruments allow comparisons of results across disease groups and different studies, but may not be sensitive to specific aspects of certain conditions. Additionally they allow for comparisons to the general population. Alternatively, disease specific instruments are sensitive to the defining features of a specific condition, but can be narrowly focused and omit other more global variables. Literature relating to this topic is far from conclusive. Some studies suggest that generic instruments are equal to, if not superior to disease specific measures (e.g. Parkinson *et al.*, 1993; Krabbe *et al.*, 2004). Others take an opposing standpoint, concluding that disease specific measures are more sensitive to change (Jenkinson *et al.*, 1997) and are superior in distinguishing clinically important differences (Bessette *et al.*, 1998). With so little concordance amongst the literature it is unsurprising that some suggest the employment of both types of measure when conducting research (Leong *et al.*, 2002)

(3-8) Cultural and language adaptations: The cross-cultural adaptation of instruments involves 2 key steps. Firstly the assessment of conceptual and linguistic equivalence, and secondly re-validation of the instrument's psychometric properties. The former is achieved through a series of forward and back translations. Conceptual equivalence relates to 'equivalence in relevance and meaning of the same concepts being measured in different cultures and / or languages', and linguistic equivalence relates to 'equivalence of question wording and meaning in the formulation of items, response choices, and all aspects of the instrument and its applications' (Scientific Advisory Committee of the Medical Outcomes Trust, 2002). Once this process is complete the second key step of undertaking a reassessment of the instrument's psychometric properties can be taken. These steps are clearly time-consuming and costly, and effectively involve the same processes that make up designing a new questionnaire, (apart from generation of items is replaced with translation of them) and have lead to some questioning the viability of cross-cultural adaptation (i.e. Streiner and Norman, 2000). The benefits of translation, however, are that comparisons can be made across nations, continents and cultures, and major projects to develop scientifically sound measures such as the WHOQOL project have been undertaken with this in mind (Skevington & Tucker, 1999).

The benefits of taking a cross cultural approach can be seen in some highly significant pieces of research that have recently emerged. Among the most noteworthy of these are the Longitudinal Investigation of Depression Outcomes Study, which followed participants from Israel, Brazil, Australia, Spain, Russia, and the USA (Fleck *et al.*, 2005; Chisolm *et al.*, 2003; Herman *et al.*, 2002; Simon *et al.*, 2002), and the EPSILON Study comparing the needs of schizophrenia patients in five European countries (Knudsden *et al.,* 2000; McCrone *et al.*, 2001). The European KIDSCREEN programme focuses specifically on children and adolescents aged 8-18, with the aim of developing a standardised HRQoL instrument for use in national and European health research (Herdman *et al.*, 2002; Ravens-Sieberer *et al.*, 2001). The psychometric properties of this developing instrument, and the validity of its use across European countries appears highly promising (Ravens-Sieberer *et al.*, 2004; Symone *et al.*, 2004). Finally, with the short-form WHOQOL-Bref instrument (WHOQOL Group 1998) now having been translated into nearly 50 languages (Skevington *et al.*, 2004) it appears that the cynicism demonstrated by e.g. Streiner and Norman (2000) is an opinion shared by the minority.

(3-9) Chapter Summary: This chapter has given an overview of the many techniques, traditional and modern, used in the design and administration of survey instruments. There are advantages and disadvantages with most, and literature makes clear that few are used in isolation. The following chapter illustrates this in reporting the further development of the PIIS, where a number of the techniques discussed in this chapter are employed. Reference has also been made to the importance of the psychometric principles that underlie sound scientific measurement, and chapter 5 considers many of these in detail in the psychometric evaluation of the revised scale.

Chapter 4: Development & Pre-Testing of the Revised Parental Illness Impact Scale (PIIS-R)

(4-1) Ethical Approval: Approval for the experimental research presented in this thesis was granted by the Joint Research Ethics Committee of National Hospital for Neurology & Neurosurgery and the Institute of Neurology, Queen Square, London. It had originally been intended to incorporate a control group of adolescent and adult children with healthy parents in order to make comparisons with children of neurologically affected parents. Permission for this was not granted as the committee felt that the proposed 'snowballing' technique for recruitment of a control group was not appropriate. Considerable scrutiny was made of the methods incorporated in the ethics proposal, as the committee was not familiar with established procedures incorporated in research with children, and it was suggested that advice be taken from the ethics committee at Great Ormond Street Hospital. Approval was finally granted on the premise that a dedicated phone number be available to participants should any participants find completing the questionnaires upsetting.

(4-1-i) Background to chapter: The Parental Illness Impact Scale (PIIS) was initially developed by the author as part of an MSc project, and based on the results of a qualitative study conducted by Roger Grimshaw for the U.K. Parkinson's Disease Society (1991). The main findings of this research were discussed in chapter 1, and the full report can be viewed in appendix F. Through a basic content analysis of this report, version 1 of the PIIS was constructed using a quality of life model comprising of 75 questions, 53 answerable on a 5-point Likert scale, and a further set of 22 dichotomous questions. Two versions of the questionnaire were developed, one for age group 11-17 (see appendix A-i), the other for ages 18 and over (see appendix A-ii). The two differ only in the language incorporated in the 11-17 year-old version, which is considered more developmentally appropriate for this group. This preliminary instrument was administered to 89 children of parents with Parkinson's disease and subjected to psychometric analysis resulting in a questionnaire of 60 items, 38 answerable on a 5-point Likert scale, and 22 dichotomous questions (PIIS version 2). The adolescent instrument can be viewed in appendix A-iii, and the adult instrument in appendix A-iv. The authors concluded that the instrument showed satisfactory internal consistency and validity. The limitations of this instrument, in particular weaknesses in the method of item selection, and the sample size employed in subsequent analysis, have been recognised by the authors (Schrag *et al.*, 2004).

(4-1-ii) Aims of chapter: The aims of this chapter are twofold, and aim to address weaknesses in the initial development of the PIIS through incorporation of a number of recognised methods of survey methodology.

Aim 1: To ensure all themes relevant to the impact of parental illness are included in the PIIS through a more rigorous process of item generation, and thereby establish sound content validity. Two procedures will be employed:

- Key informant interviews
- Literature review

Aim 2: To conduct instrument pre-testing procedures in order to identify problematic areas within the revised PIIS. Two procedures will be employed:

- c) Expert review
- d) Cognitive interviewing

A summary of the sequence of these procedures as discussed below can be viewed in table 4.1

(4-2) Item generation for the PIIS: Investigation to ensure all themes relevant to parental illness were incorporated in the PIIS was undertaken through key informant interviews and literature review as reported in the following sections.

(4-2-i) Key informant interviews: Eighteen adolescent and adult children, aged 11-52, of parents with PD were invited to participate in a semi-structured interview as a means of confirming or otherwise the contents of the preliminary instrument discussed above. The interview explored 15 dimensions identified as relevant from the preliminary study reported above. These included the emotional and behavioural impact of parental illness on the child, relationships with family and friends, levels of support, and future implications for the child of their parent's condition. Participants were asked to discuss these dimensions in terms of how they felt at the time of their parent's diagnosis, their current feelings, and how they perceived the future. A record of each interview was noted by the interviewer (DM). There was no time limit, and participants were asked at the end to contribute any further information they deemed relevant and not covered in the interview. A basic content analysis of interview data was conducted to reveal any new themes or specific issues not already contained within the preliminary instrument. The schedule for the interview can be seen in appendix B-i and participant transcripts in appendix B-ii.

Phase of research	Procedure	PIIS adjustments
Key informant interviews & literature review for development of PIIS Version 3 *Appendix B*	Semi-structured interviews with 18 participants. Review of current research literature, and relevant literature provided by support groups and charities. Additional themes generated incorporated as new items, in conjunction with review of current items to form PIIS Version 3	***Additional items generated for PIIS version 3 (v3)*** • Three global health questions relating to physical health, emotional health and quality of sleep (v3 items 1, 2 & 3). • Six items relating to emotions of sadness, anger, fear, anxiety, jealousy and guilt (v3 items 4, 5, 6, 7, 8, & 9). • Four items relating to personal behaviours of arguing, disruptive behaviour, lying, and general behaviour (v3 items 10, 11, 12, & 13). • Four 'positive' items relating to understanding of illness, coping skills, dealing with problems, and independence (v3 items 20, 21, 22 & 23). • Item relating to bullying and teasing of the child as a result of parental condition (v3 item 51). • Two items relating to financial impact on the family and impact on the family as a unit (v3 items 60 & 63). • Two dichotomous items relating to feelings of anger and anxiety, and the provision of counselling as a family (v3 items 69 & 74). ***Adjustment to dichotomous items from PIIS version 2 (v2)*** • Three items adjusted to scale variables; feelings of obligation in caring for the affected parent (v2 item 57 to v3 item 42), decision to leave home (v2 item 60 to v3 item 55), increased sense of maturity (v2 item 56 to v3 item 19). • Four items relating to talking about the parental condition (v2 items 44, 45, 46 & 47) replaced with single item (v3 item 67) due to repetitive nature. • Item 55, relating to involvement in helping around the parental home, removed due to duplicated scale variables under v3 subscale 'at home'. • Item 59, relating to experiencing 'difficult feelings' at parent's diagnosis, removed due to lack of clarity. • Item 41, relating to information about parental condition, removed due to duplication in items 39 and 40. • Item 58 removed due to addition of three scale variable global health items (v3 items 1, 2 & 3).
Expert review of PIIS Version 3 *Appendix C*	Review of adjusted PIIS by 17 experts. Analysis of responses by two researchers. Action based on relevance, concurrence between participants, methodological appropriateness, and previous KIIs.	• Removal of items 6, 9, 10, 11,12,13, 18, 23, 28, 31, 32, 34, 35, 37, 47, 52, 53, 61, 62, due to similarity or duplication with other items, or irrelevant to the QoL of the respondent. • Alterations to subscale stems. • Double-barrelled questions altered to single item. • Adoption of underlining rather than bold type for the purpose of emphasis. • Adoption of full terms such as 'for example' rather than the abbreviated e.g. • Addition of visual analogue scale. • Addition of item relating to spirituality (v4 item 27). • Addition of item relating to fears of developing parental condition in the future (v5 item 42).
Cognitive interviews for PIIS Version 4 *Appendix D*	Eight interviews to confirm consistency of item interpretation. Analysis of responses by two researchers. Action based on concurrence between participants.	• Removal of item 30 due to difficulties with interpretation and similarity to item 26 • Removal of item 33 due to inappropriate terminology and duplication • Removal of item 36 due to difficulties with interpretation • Adoption of two-week time reference based on participant responses

Table 4.1: Summary of item generation and pretesting procedures

(4-2-ii) Literature review: A review was undertaken of current scientific literature (as discussed in chapter one), and also literature provided by support groups and charities. Literature reviewed from support groups and charities included that produced by the Parkinson's Disease Society, American Parkinson's Disease Association, Parkinson Foundation of Canada, MS Society of Great Britain & Northern Ireland, MS Trust, Stroke Association, Motor Neurone Disease Association, Huntington's Disease Association, and Alzheimer's Society.

(4-2-iii) Results: KIIs and literature review resulted in the addition of and alteration to a number of items. Three global health questions relating to physical and emotional health and quality of sleep were added, as employed in many questionnaires focusing on quality of life. These items replaced the dichotomous question relating to health on the original version (item 58). Six items were added relating to emotions of sadness, anger, fear, anxiety, jealousy and guilt. A further four items relating to personal behaviours of arguing, disruptive behaviour, lying, and general behaviour were also added. Due to the propensity for studies into parental illness to focus on the negative impact (Newman, 2003) and recognition that there can be positive aspects (e.g. Gates & Lackey, 1998; Lewis *et al.,* 1985) four items were incorporated to reflect this. These items relate to understanding of illness, coping skills, dealing with problems, and independence. An item was added relating specifically to physical rather than global activities with the affected parent. An item was also added regarding bullying and teasing of the child as a result of their parent's condition. A further two items were added relating to financial impact on the family and impact on the family as a unit.

The 22 dichotomous items at the end of the original version of the PIIS were reviewed in order to reduce their number and develop them into items answerable on the 5 point Likert scale employed in the first part of the instrument. Three items relating to feelings of obligation in caring for the affected parent (item 57), the decision to leave home (item 60), and increased sense of maturity (item 56) were identified. As discussed, item 58 relating to the respondent's health was removed and replaced at the beginning of the revised instrument with three global health questions.

Four items relating to support and talking about the parent's condition (items 44, 45, 46 & 47) were considered repetitive and replaced with a single item 'do you feel you have all the support you need from friends and family?'. A question relating to

involvement in maintaining the parental home (item 55) was removed as this was duplicated in the main body of the questionnaire under sub-scale 'at home'. Item 59, relating to experiencing 'difficult feelings' at the parent's diagnosis was removed due to lack of clarity in what was being asked. Item 41, relating to information about their parents condition was removed as this was duplicated in items 39 and 40. Finally two additional dichotomous items were added on the basis of the literature review, relating to dealing with feelings of anger and anxiety, and the provision of counselling as a family.

As a result of this process the PIIS (version 3) became a 77 instrument, with 63 items answerable on a 5-point Likert Scale, and 14 dichotomous questions. The adolescent version can be viewed in appendix A-v, and the adult version in appendix A-vi.

(4-3) Pretesting of the PIIS:

(4-3-i) Expert review

(4-3-i-a) Method: Letters of invitation were sent to 29 experts, with follow-up letters sent some 4-6 weeks later. Experts were selected from 4 different fields (Parkinson's disease, multiple sclerosis, stroke / head injury, and quality of life) to gain as wide a cross-section and diversity of opinion as possible. Inclusion criterion for expert reviewers was based on their having established significant expertise in their relevant field, based on both their current academic or clinical post, and their publication record. Experts who were familiar with the research project were not included in the review process. Participants were asked to complete a brief questionnaire (appendix C-i) in relation to their opinion of both the adolescent and adult versions of the PIIS, and then add any other comments they felt relevant.

Completed responses were received from 17 participants, 3 declined to take part, and no response was received from 9. This equates to a response rate of 59%. A qualitative analysis was undertaken by two researchers (DM & CS). Comments provided by participants were analysed by item although were separated according to which version of the questionnaire they related to. Many comments were directed at both versions of the PIIS. Each comment was individually reviewed and an agreed course of action taken based on relevance, concurrence between participants, methodological appropriateness, and previous feedback from KIIs.

(4-3-i-b) Results: A detailed analysis of participants' item comments and global comments for both versions of the PIIS, as well as action taken, is provided in appendix C-ii.

A number of alterations were made on the basis of the review. Nineteen questions were removed due to being similar or duplicated items, or not relevant to the QoL of the respondent. A number of changes were made to section stems, and all double-barrelled questions were altered to single item. Amongst the other recommendations incorporated were the use of underlining rather than bold type for the purposes of emphasis, and the use of full terms such as 'for example' rather than the abbreviated 'e.g.'. On the basis of expert recommendations a visual analogue scale was incorporated.

Two additional items were suggested by the reviewers. Firstly an item relating to spirituality, and secondly an item relating to fears of developing the parental condition in the future. The former of these was included in the abbreviated PIIS, but the latter was omitted in error until after the cognitive interview phase. As a result of the expert review the PIIS (version 4) stood as a 58 item instrument, 44 answerable on a 5 point Likert scale, and 14 dichotomous questions. The adolescent version can be viewed in appendix A-vii, and the adult version in appendix A-viii.

(4-3-ii) Cognitive interviewing

(4-3-ii-a) Method: The working paper published by Gordon Willis of the United States Office of Research Methodology, National Centre for Health Statistics (Willis, 1994) was adopted as a template for the analysis reported here. Details of this were discussed in chapter 3. Two main cognitive interview methods are highlighted by Willis; 'think aloud' interviewing, and the probing technique, the latter being the primary method adopted here.

Two groups of participants took part in order to analyse both the adolescent and adult versions of the PIIS. Five adolescent children (mean age 14.2 years, range 11-17), and 3 adult children participated (mean age 35.3 years, range 31-39). These numbers are sufficient within the guidelines reported by Willis (1994). Adult participants were sent a postal invitation to take part. Adolescent participants were contacted via one or both of their parents in order to gain parental consent. Response rate was 100%. Participants were selected on the basis of their having

taken part in the previously discussed KIIs, and as such, there may well be a degree of sample bias.

Participants were first asked to read the instruction panel aloud, and to say whether they found this clear and easy to understand. They were then instructed to read each item from the PIIS aloud and to answer the question as they felt appropriate by placing a tick by the relevant response option. After doing so, cognitive techniques were applied.

The probing technique was the primary cognitive method used, specifically the use of the *standard probes* outlined below.

Comprehension / interpretation probes: All participants were asked to define, in the context in which they appeared, the terms:

- 'physical health' (item no 1)
- 'feelings' (item 2)
- 'neglected' (item no 7)
- 'relationships' (item no 10)
- 'independence' (item no 16)
- 'responsibility' (item no 17)
- 'household chores' (item no 19)
- 'religious beliefs' (item no 27)
- 'close' (item no 30)
- 'resentful' (item no 31)
- 'mature' (item no 33)
- 'sympathetic' (item no 34)
- 'financially' (item no 44)
- 'counselling' (item no 55)
- 'outside help' (item 56)
- 'local services' (item no 58)

Paraphrasing: All participants were asked to repeat, in their own words, item numbers:

- **25** - How often do you do you feel any problems you may have had with your parent with PD are due to their illness rather than anything else?

- **36** - How often do you feel that as a result of your parent's PD you are better at finding ways to deal with problems?
- **40** - To what extent do you feel that your own future may be different than it otherwise might have been because of your parent's PD?

General probes: All participants were asked:

- 'was that easy or hard to answer?' after completing each item on the questionnaire
- 'how did you arrive at that answer?' after completing items 3 and 22.
- 'you appeared to hesitate before answering – what were you thinking about?' where the participant's response warranted such investigation.

Where participants appeared, in the opinion of the interviewer, to experience further difficulties with any item based on their verbal report or non-verbal behaviour, the interviewer pursued this further in the form of *individual probes*, in order to clarify any pertinent issues.

(4-3-ii-b) Results: A full and detailed analysis of interviews conducted with adolescent children and adult children can be seen in appendix D.

A small number of alterations were made as a result of the cognitive interviews. Most significantly three items (30, 33, & 36) were removed, and a two-week time reference was incorporated. Participant responses showed there was a clear necessity for a time referent for a number of items, and items where specific participant responses did not suggest a time-frame was required, but one has been added for consistency are highlighted by *** in the appendix. All participants reported finding the instruction panel clear. There were no reports of any difficulties with response options or with subscale stems. Although a minority of participants did find it difficult to articulate the specific meaning of a particular word, their general understanding of the question did, in most cases, appear clear. All subjects reported finding the instructions to section C, and completion of the visual analogue scale straightforward.

(4-4) Final survey instrument: As a result of the procedures reported above the PIIS (version 5) became a 56 item instrument, consisting of 42 items answerable on a 5-point Likert scale, and a further 14 dichotomous items. Both versions of the instrument have a Flesh Kincaid grade level of 6.0 (age 11) and a Flesch reading

ease score of 73.0. The instrument for ages 11-17 can be seen in appendix A-ix, and for those aged 18 and above in appendix A-x.

(4-5) Discussion: The aims of this chapter were to ensure the PIIS contained all themes relevant to the impact of parental illness, and to pre-test the revised instrument as a means of identifying problematic areas. Following key informant interviews and literature review the PIIS was subject to expert review and cognitive interviews, as summarised below.

Eighteen key informant interviews and literature review resulted in the generation of 20 additional items (18 scale, and 2 dichotomous). The review conducted of the original PIIS as part of this process resulted in adjusting 3 dichotomous items to scale variables, with seven dichotomous items removed as a result of duplication with existing or newly created questions. The resulting pool of 77 items was subject to expert review. Extensive comments were received from seventeen experts in a variety of fields and a number of changes made on the basis of this procedure. Nineteen items were removed and two new items generated. Additional changes were incorporated, including adjustment to subscale stems and addition of a visual analogue scale. The resulting questionnaire was then further pre-tested through 8 cognitive interviews. As a result three further items were removed due to duplication and difficulties with interpretation, and a two week time reference was incorporated where relevant.

The procedures reported above suggest the final pool of 55 items of the PIIS show strong face and content validity, as well as providing few problems for respondents. The following chapter reports a comprehensive evaluation of the psychometric properties of the instrument.

Chapter 5: Psychometric Evaluation of the Revised Parental Illness Impact Scale (PIIS-R)

(5-1) Background: Previous chapters have discussed the development and preliminary validation of the Parental Illness Impact Scale (PIIS), and limitations of the instrument following this process. Chapter 4 specifically discussed the second phase of the instrument's development and pre-testing. This chapter reports the subsequent psychometric analysis of the revised Parental Illness Impact Scale (PIIS-R).

(5-1-i) Aims and hypotheses: The aims of this chapter are to provide a comprehensive psychometric evaluation of the PIIS-R to include:

1. *Content & face validity* – by analysis of qualitative data previously reported and analysis of participant comments.
2. *Construct validity* – through principle components analysis to identify appropriate subscales.
3. *Concurrent validity* – through assessing correlations with previously validated instruments assessing similar constructs.
4. *Discriminant validity* – through measuring whether scores reflect disparities between constructs that are known to differ.
5. *Internal consistency* – by obtaining measures of Cronbach's alpha for each subscale.
6. *Test-retest reliability* – by re-administration to the same subjects after one month.

Specifically it is hypothesised that the PIIS-R will:

a) Demonstrate sound validity through assessment of content, face, construct, concurrent and discriminant validity.
b) Demonstrate strong reliability through measurement of internal consistency and test-retest reliability.

(5-2) Materials & methods:

(5-2-i) Sample recruitment: The sample consisted of adolescent (age 11-17) and adult (age 18 and above) children of parents with PD, MS and stroke. Participants were recruited via a number of avenues. Children of parents with Parkinson's that had participated previously in the study of Schrag *et al* (2004a; 2004b) were invited to take part. The study was also advertised in The Parkinson, the quarterly publication of the UK Parkinson's Disease Society, and YAPMAG the quarterly publication of Young Alert Parkinson's, Partners and Relatives (YAPP&Rs), a support group dedicated to young-onset PD patients and their families. Children of PWMS were recruited via the support charities the Scottish MS Society and the MS Trust. Children of parents with stroke were recruited via the young stroke charity Different Stroke. On responding to relevant advertisements, family members were each sent an information sheet (appendix F-i), and consent form (appendix F-ii). Children under the age of 18 were required to have their consent form countersigned by a parent or guardian.

Parents and spouses or carers were also invited to participate in this study to allow assessment of parental factors such as level of disability and mental health and their impact on child QoL, as reported in subsequent chapters. Inclusion of PWP was based on their having received a confirmed clinical diagnosis of Parkinson's disease, and having at least one child aged eleven or above. Patients who subsequently received an alternative diagnosis (e.g. progressive supranuclear palsy), or received one during the study, were excluded, as were any other family members. PwMS were included on the basis on their having received a clinical diagnosis of multiple sclerosis (primary progressive, secondary progressive, relapsing-remitting, progressive relapsing), and having at least one child aged eleven or above. Stroke patients were recruited on the basis of them having suffered a focal stroke, and that any subsequent cognitive impairment did not impede them from completing the questionnaire battery. Participants required at least one child aged eleven or above.

A total of 331 children and parents who agreed to take part returned their questionnaires, a response rate of 76%. A summary of participants by illness group can be seen in tables 5.1, 5.2, and 5.3.

Illness Group: **PD**	Administered	Received	Response Rate
11-17	26	16	62%
18+	93	66	71%
Patient	50	41	82%
Spouse / carer	44	30	68%
Total	**213**	**153**	**72%**

Table 5.1: Participants of families affected by PD

Illness Group: **MS**	Administered	Received	Response Rate
11-17	32	25	78%
18+	46	38	83%
Patient	41	36	88%
Spouse / carer	32	26	81%
Total	**151**	**125**	**83%**

Table 5.2: Participants of families affected by MS

Illness Group: **Stroke**	Administered	Received	Response Rate
11-17	16	11	69%
18+	23	15	65%
Patient	18	14	78%
Spouse / carer	17	13	77%
Total	**74**	**53**	**71%**

Table 5.3: Participants of families affected by stroke

The total sample size reported in this chapter is 169; 81 children of parents with PWP, 62 of PWMS, and 26 children of parents who had suffered a stroke. Two children were excluded from analysis due to returning their questionnaires late, but included in analyses reported in chapters 6 & 7. Questionnaires were mailed to children, either individually had they left home, or as part of a large pack including batteries for siblings and parents if they remained in the parental home. Each individual questionnaire was sent in a sealed envelope also containing a return stamped, addressed envelope so as to maximise the likelihood of maintaining the confidentiality of respondents from the same family.

(5-2-ii) Questionnaires: Questionnaire batteries were assembled to allow assessment of concurrent and discriminant validity of the PIIS, and to allow analysis of a number of variables in participant samples reported in later chapters. Batteries for adolescent and adult children differed to account for developmental stage. Particular attention was given to the reliability of instruments selected (as outlined in chapter 3), and reliability data is given for each instrument described. Table 5.4 summarises each battery, and is followed by a description of each questionnaire.

Adolescent Child	Adult Child
Parental Illness Impact Scale	Parental Illness Impact Scale
Youth QoL Scale	EUROQoL-5D
Birleson Depression Self Rating Scale	Beck Depression Inventory
Rosenberg Self-Esteem Questionnaire	Rosenberg Self-Esteem Questionnaire
Parentification Questionnaire-Youth	Parentification Questionnaire -Adult
Family Crisis Orientated Personal Evaluation Scales	Family Crisis Orientated Personal Evaluation Scales
Family Environment Scale	Family Environment Scale
Social Support Scale for Children	Social Support Scale Short R
Inventory of Parent & Peer Attachment	

Table 5.4: Questionnaire batteries for adolescent and adult participants

(5-2-ii-a) Questionnaire battery for ages 11-17: Those participants aged between 11 and 17 were asked to complete a booklet of questionnaires for adolescent children in the order presented below:

- ***Parental Illness Impact Scale - 11-17*** (PIIS): As detailed in chapter 4 and seen in appendix A-ix. Reference to parental condition is altered dependent on parental illness group of participant (i.e. PD, MS or stroke).
- ***Youth Quality of Life Instrument*** (YQOL-R; Topolski *et al.*, 2002): A recently developed generic instrument, the YQOL-R has been validated in a large sample of adolescents aged 12-18, and has been shown to have good psychometric properties. The instrument contains 41 items with an 11 point response scale, yielding a QoL profile across the four domains of Self, Environment, Relationships and General QoL, and demonstrates high reliability across all 4 subscales (α =.81-.89) and total QoL score (α = .94). The instrument can be viewed in appendix E-i.
- ***Birleson Depression Self Rating Scale*** (DSRS; Birleson, 1981; Birleson *et al.*, 1987): Developed in recognition that the Beck Depression Inventory is over sensitive for children, the DSRS is regarded as a reliable and valid tool in assessment of adolescent depression, demonstrating high internal consistency (α =.90; Ivarsson *et al.*, 1994; Ivarsson & Gillberg, 1997). The instrument has been validated in a number of studies with children ranging between the ages of 8-18 (e.g. Ivarsson *et al.*, 1994; Fundudis *et al.*, 1991; Ivarsson *et al.*, 2002) and totals eighteen items, each having the three response choices of 'Most of the Time', 'Sometimes' and 'Never'. The maximum score is 36, with higher scores indicative of increased levels of depression. The instrument can be viewed in appendix E-ii.

- ***Rosenberg Self-Esteem Questionnaire*** (SEQ; Rosenberg, 1965): A short 10-item questionnaire that measures feelings of self-deprecation and self-worth. The instrument has been widely used in adolescent populations aged 11 and above (e.g. Perrin *et al.*, 2000; Furnham & Cheng, 2000; Lanz *et al.*, 1999). Response categories comprise a 4-point agree-disagree Likert scale. The maximum score is 40, with higher scores reflecting more positive self-esteem. The SEQ has been shown to demonstrate good reliability in the range α =.77-.88 (Blascovich & Tomaka, 1991), and can be viewed in appendix E-iii.

- ***Parentification Questionnaire – Youth*** (PQ-Y; Godsall & Jurkovic, 1995): A relatively new area of research, the parentified child is defined as one that is 'compelled to perform the role of parent at the expense of their own developmentally appropriate needs and pursuits' (Chase, 1999). This 20 item instrument incorporates a ***yes*** / ***no*** response option demonstrating good reliability (α =.75-.83; Godsall & Jurkovic, 1995). The PQY has been shown to capture low self-esteem and risk behaviours in ages 10-17 (Godsall & Jurkovic, 1999), and to reflect the relationship between family coping and trauma symptomatology in a cohort aged 10-16 (Green, 2000). The instrument can be viewed in appendix E-iv.

- ***Family Crisis Orientated Personal Evaluation Scales*** (F-COPES; McCubbin *et al.*, 1981): Developed as part of the Family Stress, Coping and Health Project, F-COPES is designed to record problem-solving attitudes and behaviours which families develop to respond to problems or difficulties. This 30 item instrument has been extensively validated (α =.71 -.86; McCubbin *et al.*, 1981) and used with families representing all stages of the life cycle from adolescence onwards (e.g. Navia & Ossa, 2003; Minnes *et al.*, 2000; Smith *et al.*, 1991). The instrument can be viewed in appendix E-v.

- ***Inventory of Parent and Peer Attachment*** (IPPA; Armsden & Greenberg, 1987): Devised to measure child / adolescent attachment to parents, this instrument explores communication, trust, and alienation. The instrument, containing 28 items, each with a 5-point Likert scale response option, has been fully validated and administered to adolescents between the ages of 12-21 (e.g. Armsden & Greenberg, 1987; Beitel & Cecero, 2003; Paterson *et al.*, 1995). The IPPA is widely used due to the established high reliability of the scale (α =.86-.91; Benson *et al.*, 2006), and can be viewed in appendix E-vi.

- ***Family Environment Scale*** (FES; Moos & Moos, 1980): A well established and widely used 90 item instrument, with acceptable internal consistency (α =.61-.78) and TRT (r=.52-.91; Moos & Moos, 1980; Moos, 1990). The FES incorporates a ***true*** or ***false*** response set, and assesses the three dimensions of Relationships, Personal Growth and System Maintenance, these being broken down further into 10 subscales. The instrument can be viewed in appendix E-vii.

- ***Social Support Scale for Children*** (SSSC; Harter, 1985): Designed as a result of research that identified children aged 8 and older as being capable of making a judgement about their global self-worth, the SSSC measures social support and positive regard a child may receive from parents, classmates, teachers and close friends. Comprising 21 items, the instrument is widely used in child populations ranging in ages from 8-18, (e.g. Harter, 1985; Battles & Wiener, 2002), and demonstrates good reliability (α =.74-.88; Harter, 1985). The instrument can be viewed in appendix E-viii.

***(5-2-ii-b) Questionnaire Battery for ages 18 and above*:** Participants aged 18 and above were asked to complete a booklet of questionnaires for adult children in the order presented below:

- ***Parental Illness Impact Scale 18+*** (PIIS): As detailed in chapter 4 and seen in appendix A-x.

- ***EUROQoL-5D*** (EUROQOL GROUP, 1990): A generic, 5 item questionnaire that also incorporates a visual analogue scale (range, 0: worse health status, 100: best health status), to indicate general health status. A unique health state is derived by combining responses from each of the five questions. Any one of the possible 243 health states that can be derived is converted to a summary score, higher scores indicating superior QoL. The instrument has sound reliability for both the utility (r=.73) and VAS (r=.70) components (Hurst *et al.*, 1997), and can be viewed in appendix E-ix.

- ***Beck Depression Inventory*** (BDI; Beck *et al.*, 1961): A widely used 21 item inventory covering somatic, affective, and behavioural symptoms of depression. Response options are 0-3, leading to a maximum possible score of 63. Higher scores are indicative of higher levels of depression. Cut-off scores generally employed are 0-9 indicating no depression, 10-17 mild depression, 18-24 moderate depression, and 25 and above indicating severe depression. A review of studies incorporating the BDI has shown it to display good internal consistency

(α =.73-.92) in non-psychiatric samples (Beck *et al.*, 1988). The instrument can be viewed in appendix E-x.

- ***Rosenberg Self-Esteem Scale*** (SEQ): As described previously and seen in appendix E-iii

- ***Parentification Questionnaire – Adult*** (PQ-A; Sessions & Jurkovic, 1986). This 21 item instrument is the adult version of the PQ-Y described previously. The instrument incorporates ***yes / no*** response options yielding a retrospective parentification score, and shows good internal consistency (α =.77-.88) and test-retest reliability (r= .86; Goglia *et al.*, 1992). The instrument can be viewed in appendix E-xi.

- ***Family Crisis Orientated Personal Evaluation Scales*** (F-COPES): As described previously and seen in appendix E-v.

- ***Family Environment Scale*** (FES): As described previously and seen in appendix E-vii.

- ***Social Support Questionnaire Short R*** (SSQSR; Sarason *et al.*, 1987): This six item instrument asks respondents to list a maximum of 9 people upon whom they can count for a range of emotional support issues. Respondents are also asked to rate their satisfaction with this support on a six-point scale, with higher scores indicating greater satisfaction. Developed as a shortened version of the Social Support Questionnaire (Sarason *et al.*, 1983), the instrument demonstrates excellent internal consistency (α =.96) and test-retest reliability (r=.85; Sarason *et al.*, 1987). The instrument can be viewed in appendix E-xii.

(5-2-iii) Statistical analysis: Data was entered into 'SPSS' and coded in order to maintain confidentiality. Sub-scale and summary scores for established instruments were calculated according to respective scoring algorithms. A principal components analysis (PCA) was performed on the PIIS in order to assess construct validity and to confirm the underlying a priori dimensions. Analysis post-PCA was based on the sub-scores of the principal components (PCs) identified and retained. Dimension scores were summed to obtain an overall total score. Internal consistency was estimated for each of the final PCs using Cronbach's alpha coefficient. As a test of concurrent validity and discriminant validity Pearson's product-moment or Spearman rank correlation coefficients (as appropriate depending on sample size or data distribution) were calculated between the PIIS and other measures detailed above. Correlations were also calculated to assess test-retest reliability, and the validity of the visual

analogue scale incorporated in the PIIS. Data were checked for presence of outliers and normality of distribution prior to statistical analysis. Distribution of data was analysed using Kolmogorov-Smirnov and Shapiro-Wilk (for sample size less than 30) tests of normality.

(5-3) Results

(5-3-i) Description of sample: The total sample consisted of 169 participants. Sociodemographic data are presented in table 5.5.

Sample size	169
Gender M:F	75:94
Mean age (*y*)	24.31 (*SD* = 9.47)
n = adolescent (11-17)	51
n = adult (18+)	118

SD = standard deviation; *y* = years

Table 5.5: Description of sample

(5-3-ii) Missing value analysis

A missing value analysis was conducted on all instruments administered to ensure the validity of subsequent tests in the psychometric evaluation of the PIIS-R. Table 5.6 presents the frequency of missing data for instrument totals and relevant subscales. The distribution pattern by item can be viewed in appendix G. Missing values for the revised PIIS are reported in a later section

All instruments meet the required criteria of less than 10% missing data (Bennet, 2001), apart from the Social Support Scale for Children. The high value for this instrument is explained in 10 respondents choosing to omit this questionnaire completely. This may have been due to respondent burden as this was the last questionnaire in the battery, or the awkward nature of the response options for this instrument. Such data has been described as 'not missing at random' and is not predicted by other variables in a given dataset (Bennet, 2001). Of those participants who did complete the questionnaire just one response was missing from a total response pool of 984 (0.11%).

Instrument	Frequency of missing data (%)
Youth QoL Scale	0.62
Birleson Depression Self Rating Scale	0.00
Rosenberg Self-Esteem Questionnaire	1.80
Parentification Questionnaire-Youth	0.00
Social Support Scale for Children	19.70
Inventory of Parent & Peer Attachment	0.42
EUROQOL	2.50
Beck Depression Inventory	3.45
Parentification Questionnaire -Adult	1.38
Social Support Scale Short R	6.15
Family Crisis Orientated Personal Evaluation Scales	3.02
Family Environment Scale	4.01
Instrument Subscales	
Youth QoL Scale:	
Subscale 1: General quality of life	1.31
Subscale 2: Self	1.41
Subscale 3: Relationships	0.14
Subscale 4: Environment	0.00
Family Crisis Orientated Personal Evaluation Scales:	
Subscale 1: Acquiring social support	2.94
Subscale 2: Reframing	3.02
Subscale 3: Seeking spiritual support	2.94
Subscale 4: Mobilising family support	3.23
Subscale 5: Passive appraisal	3.10
Family Environment Scale:	
Subscale 1: Cohesion	4.03
Subscale 2: Expressiveness	4.68
Subscale 3: Conflict	3.70
Subscale 4: Independence	3.70
Subscale 5: Achievement orientation	4.35
Subscale 6: Intellectual-cultural orientation	3.86
Subscale 7: Active-recreational orientation	4.35
Subscale 8: Moral-religious emphasis	4.35
Subscale 9: Organisation	3.70
Subscale 10: Control	3.37

Table 5.6: Missing value analysis of instrument total and subscale scores

(5-3-iii) Psychometric properties of the PIIS

(5-3-iii-a) Content and face validity: By the nature of the way the PIIS was constructed through the qualitative procedures reported in Chapter 4, it is reasonable to conclude that the instrument shows strong content and face validity. This is further emphasised by there being no comments relating to missing areas / items in space given over to participants at the end of the questionnaire battery.

(5-3-iii-b) Construct validity: Principal components analysis (PCA) – The sample met the criteria for the use of PCA. The sample was normally distributed (z=.854, p = .459), sample adequacy was high (KMO = .862), and Bartlett's test of sphericity calculates the model (PCA) to be appropriate (x^2 = 3513.95, p = 0.00). Missing data values were calculated using the expectation maximisation (EM) algorithm. EM is regarded as the most efficient method by which to produce good estimates of variability in data using SPSS (Bennet, 2001). Item-total correlations were calculated for the first 42 items of the PIIS identifying 39 items with r values significant at 0.01. Item 30 was removed due to level of non-response (29.2%). Correlations are presented in table 5.7.

Item no	Item-total correlation	Item no	Item-total correlation
1	.308**	22	.620**
2	.408**	23	.610**
3	.327**	24	.348**
4	.617**	25	.646**
5	.634**	26	.654**
6	.566**	27	.702**
7	.569**	28	.543**
8	.623**	29	.143 (p=.06)
9	.669**	**30**	**removed**
10	.602**	31	.486**
11	.614**	32	-.257**
12	.441**	33	.071
13	.423**	34	.743**
14	.489**	35	.618**
15	.274**	36	.563**
16	.645**	37	.534**
17	.573**	38	.495**
18	.555**	39	.569**
19	.437**	40	.466**
20	.560**	41	.524**
21	.466**	42	.439**

** Significant at 0.01

Table 5.7: Item-total correlations for PIIS items 1-42

Factor / Items and original questionnaire numbers	Factor loading	% of variance	Alpha value	No Missing Values (%)
1. Burden of Daily Help				
20 – More household chores due to parents illness	.762			10 (5.8)
19 – Household chores on a regular basis	.669			10 (5.8)
18 – Parent depends on child	.668			3 (1.7)
21 – More help than brothers or sisters	.612			1 (0.6)
26 – Have to help care for parent	.601			4 (2.3)
17 – Increased responsibility	.573			1(0.6)
39 – Affect decision to leave home	.523			1(0.6)
36 – Home more difficult than before parental illness	.345	28.55	.84	1(0.6)
2. Emotional Impact				
4 – Sad	.763			1 (0.6)
6 – Worried	.725			1 (0.6)
8 – Affected schoolwork	.660			1 (0.6)
5 – Angry	.612	6.77	.83	1 (0.6)
3. Social Impact				
9 – Spent less time with friends	.762			1 (0.6)
11 – Spent less time on social activities	.754			1 (0.6)
16 – Less independence	.646			2 (1.2)
34 – Parental illness affect own routine	.528			2 (1.2)
10 – Harms relationships with friends	.501			2 (1.2)
37 – Harms family financially	.398	6.12	.83	5 (2.9)
4. Communication & Understanding				
23 – Parent has difficulty talking about illness	.684			3 (1.7)
25 – Problems due to illness rather than anything else	.637			1 (0.6)
31 – Understand unwell parent less than other parent	.632			1 (0.6)
35 – Parent's illness affects life of whole family	.596			3 (1.7)
22 – Parent has difficulty engaging in activities	.594			3 (1.7)
27 – Annoyed about changes in parent's behaviour	.526			2 (1.2)
32 – More understanding of other illness and disability	.388	4.89	.75	2 (1.2)
5. Impact on personal future				
40 – Uncertain about future	.848			3 (1.7)
41 – Own future might be different due to parents illness	.789			2 (1.2)
38 – Independence affected in future	.748	4.32	.84	1 (0.6)
6. Friends reactions				
12 – Difficulty explaining parents illness to friends	.853			18 (10.5)
13 – Difficulty coping with friends lack of understanding	.812			18 (10.5)
14 – Embarrassed talking to friends	.619	3.53	.79	2 (1.2)
7. Parent / child relationship				
24 – Parent and child understand each other	.731			2 (1.2)
29 – Parental illness brought closer together	.651			1 (0.6)
28 – Embarrassed by parent's illness	.480	3.47	.56	2 (1.2)
8. Global well-being				
1 – Physical health	.799			1 (0.6)
3 – Sleep	.792			2 (1.2)
2 – Emotional health	.743	2.94	.73	2 (1.2)
	Instrument alpha value		.92	

Table 5.8: Principal components analysis solution, factor loadings, percentage of explained variance, Cronbach's alpha coefficients, and number of missing values.

PCA identified eleven factors with the traditionally accepted Eigenvalue of over 1 (Hutcheson & Sofroninou, 1999), explaining 68.5% of variance. Factor 9 was removed, as with just 2 items is likely to be unreliable, as were factors 10 & 11 with only one item each. The remaining 8 factors (37 items) explain 60.6% of total variance. Of those items remaining all have item-total correlations significant at .0.01 except item 29, which just fails to meet statistical significance (p=.06). Table 5.8 displays the final solution of 8 factors, factor loadings, percentage of explained variance, and Cronbach's alpha coefficients.

The eight factors retained comprise of 37 questions. Factor 1, *Burden of Daily Help* (8 items) focuses on the changing roles of children when confronted with parental illness, and the extent to which they play a major role in the maintenance of the family / parental home. Factor 2, *Emotional Impact* (4 items), highlights negative emotional feelings, while factor 3, *Social Impact* (6 items), highlights the extent to which parental illness can affect personal relationships and social development. The fourth factor, *Communication and Understanding* (7 items), addresses problems experienced between the unwell parent and the child, and the strain this places on their relationship. Factor 5, *Impact on Personal Future* (3 items), reflects the child's increased level of personal concern about their own future as their parents condition progresses. Factor 6, *Friends Reactions* (3 items), highlights children's difficulties experienced in peer group relationships and reactions of friends to their parent's condition. Factor 7, *Parent / Child Relationship* (3 items), focuses on the positive and negative reactions to parental illness, and finally factor 8, *Global Well-Being* (3 items) provides a snapshot of the child's general health. Limitations in the use of PCA are discussed in a later section. Mean scores, standard deviations and missing data values are presented in table 5.9.

	Mean score	Standard deviation	Frequency of missing data (%)
Burden of daily help	31.04	6.53	2.30
Emotional impact	14.92	3.27	0.60
Social impact	25.66	4.27	1.38
Communication & understanding	24.00	5.50	1.26
Impact on personal future	10.45	2.91	1.20
Friends reactions	13.01	2.44	6.71
Parent / child relationship	10.40	2.58	0.99
Global well-being	9.41	2.55	0.99
Total score	**155.47**	**22.05**	**1.82**

Table 5.9: PIIS mean scores, standard deviations and percentage of missing values post PCA

(5-3-iii-c) Internal consistency – Cronbach's alpha values are also presented in table 5.8. Subscale values are all satisfactory, although the value for factor 7 at .56 is markedly lower than other factors. Overall instrument value is high at .92.

(5-3-iii-d) Concurrent validity – It was hypothesised that the PIIS would correlate with alternative scales designed to measure similar or related constructs. Correlation coefficients between PIIS total scores and other scales administered are displayed in table 5.10. All are highly statistically significant. As both EUROQOL and Beck Depression Inventory data were not normally distributed, these were further tested using non-parametric calculations (Spearman's *rho*). Both results remain highly significant as shown in table 5.11.

Youth Quality of Life Questionnaire	.673**
Birleson Depression Inventory	-.667**
Beck Depression Inventory	-.620**
Parentification Questionnaire - Youth	-.598**
Inventory of Parent & Peer Attachment	.497**
Social Support Scale for Children	.481**
Rosenberg Self-Esteem Questionnaire	.435**
Parentification Questionnaire - Adult	-.395**
EUROQOL Visual Analogue Scale	.345**
Social Support Questionnaire	.328**

** Correlation significant at 0.01

Table 5.10: Correlations between the PIIS and existing fully validated scales

EUROQOL Visual Analogue Scale	.298**
Beck Depression Inventory	-.556**

** Correlation significant at 0.01

Table 5.11: Non-parametric correlations between the PIIS, EUROQOL Visual Analogue Scale and Beck Depression Inventory

Analysis was also undertaken of correlations between subscales of the PIIS and other validated instruments. Correlations with measures administered to children aged 11-17 are shown in table 5.12. Correlations between PIIS subscales and instruments administered to those aged 18 and above are shown in table 5.13.

	YQOL	DSRS	PQY	SEQ	SSC	IPPA
Burden of daily help	.235	-.293*	-.653**	.228*	.166	.330*
Emotional impact	.489**	-.611**	-.448**	.269**	.275	.342*
Social impact	.549**	-.456**	-.474**	.326**	.544**	.411**
Communication & understanding	.495**	-.474**	-.452**	.316**	.400**	.370**
Impact on personal future	.514**	-.462**	-.379**	.249**	.378*	.289*
Friends reactions	.566**	-.468**	-.195	.245**	.330*	.197
Parent / child relationship	.494**	-.406**	-.250	.251**	.260	.388**
Global well-being	.511**	-.664**	-.307*	.491**	.287	.381**

** Correlation significant at 0.01
* Correlation significant at 0.05

Table 5.12: Correlation coefficients between PIIS sub-scales and the Youth Quality of Life Questionnaire, Birleson Depression Inventory, Parentification Questionnaire – Youth, Rosenberg Self-Esteem Questionnaire, Social Support Scale for Children, and Inventory of Parent & Peer Attachment.

	EURO-QOL VAS	BDI	PQA	SSQ
Burden of daily help	.223*	-.457**	-.370**	.317**
Emotional impact	.159	-.413**	-.180	.177
Social impact	.192*	-.509**	-.266**	.143
Communication & understanding	.313**	-.470**	-.285**	.197*
Impact on personal future	.116	-.241**	-.212*	.020
Friends reactions	.237*	-.413**	-.212*	.189*
Parent / child relationship	.169	-.276**	-.154	.379**
Global well-being	.520**	-.541**	-.328**	.311*

** Correlation significant at 0.01
* Correlation significant at 0.05

Table 5.13: Correlation coefficients between PIIS sub-scales and the EUROQOL Visual Analogue Scale, Beck Depression Inventory, Parentification Questionnaire – Adult, and the Social Support Questionnaire.

Correlations coefficients were also calculated between PIIS subscales and subscales and total scores of YQOL, FCOPES, and the FES. Correlations between PIIS and YQOL subscales and total scores are given in table 5.14. All are highly statistically significant apart from correlations between a) PIIS subscale 1, burden of daily help, and YQOL subscales general quality of life, relationships, environment, and total score, and b) PIIS subscale 7, parent / child relationship and YQOL subscale environment.

PIIS \ YQOL	ss-1	ss-2	ss-3	ss-4	Total Score
ss-1	.172	.376**	.198	.172	.235
ss-2	.430**	.474**	.464**	.449**	.489**
ss-3	.431**	.558**	.556**	.514**	.549**
ss-4	.414**	.560**	.469**	.412**	.495**
ss-5	.394**	.542**	.502**	.500**	.514**
ss-6	.465**	.598**	.518**	.541**	.566**
ss-7	.494**	.505**	.539**	.263	.494**
ss-8	.470**	.517**	.453**	.436**	.511**
Total Score	.568**	.718**	.636**	.581**	.673**

** Correlation significant at 0.01
* Correlation significant at 0.05

Table 5.14: Correlation coefficients between PIIS subscales and total scores, and subscales and total scores of the Youth Quality of Life Questionnaire. A key to each subscale is given below.

KEY

PIIS Subscale	
1	Burden of daily help
2	Emotional impact
3	Social impact
4	Communication and understanding
5	Impact on personal future
6	Friends' reactions
7	Parent / child relationship
8	Global well-being

YQOL Subscale	
1	General quality of life
2	Self
3	Relationships
4	Environment

Correlation coefficients between PIIS and FCOPES subscales and total scores are given in table 5.15. PIIS subscale 3, social impact, correlates significantly with FCOPES subscales acquiring social support (r=.217, p<0.01), and passive appraisal (r=.183, p<.0.05). PIIS subscale 4, communication and understanding, correlates significantly with FCOPES subscales acquiring social support (r=.218, p<0.01), reframing (r=.202, p<0.01) and passive appraisal (r=.215, p<0.01). PIIS subscale 6, friends reactions, correlates weakly but significantly with FCOPES subscale passive appraisal (r=.183, p<.0.05). PIIS subscale 7, parent / child relationship, correlates significantly with FCOPES subscales acquiring social support (r=.231, p<0.01), reframing (r=.252, p<0.01), and passive appraisal (r=.395, p<0.01). PIIS subscale, global well-being, 8 correlates significantly with FCOPES subscales reframing (r=.212, p=0.01) and passive appraisal (r=-.218, p<0.01).

Correlation coefficients between PIIS and FES subscales and total scores are given in table 5.16. PIIS subscale 1, burden of daily help, correlates significantly with FES subscales conflict (r=-.326, p<0.01), independence (r=.253, p<0.05) and control (r=-.246, p<0.05). PIIS subscale 2, emotional impact, correlates significantly with FES subscales conflict (r=-.275, p<0.05) and control (r=-.333, p<0.01). PIIS subscale 3, social impact, correlates significantly with FES subscales cohesion (r=.244, p<0.05), achievement orientation (r=-3.85, p<0.01) and control (r=-.306, p<0.01). PIIS subscale 4, communication and understanding, correlates significantly with FES subscales expressiveness (r=.278, p=0.05) and conflict (r=-.354, p=0.01). PIIS subscale 5, impact on personal future correlates with FES subscale achievement orientation (r=.240, p<0.05). PIIS subscale 6, friends reactions, correlates significantly with FES subscales expressiveness (r=.275, p<0.05), conflict (r=-.294, p<0.05), and active recreational orientation (r=.237, p<0.05). PIIS subscale 7, parent child relationship, correlates significantly with FES subscales cohesion (r=.293, p<0.05), expressiveness (r=.299, p<0.05), conflict (r=-.309, p<0.01), and active recreational orientation (r=.268, p<0.05). PIIS total score correlates significantly and negatively with FES subscale conflict (r=-.417, p<0.01) and positively with FES subscale control (r=-.292, p<0.05).

FCOPES PIIS	Subscale 1	Subscale 2	Subscale 3	Subscale 4	Subscale 5	Total Score
1	.044	.067	-.042	-.068	.116	.052
2	.121	.054	-.073	.000	.105	.096
3	.217**	.033	-.130	-.063	.183*	.123
4	.218**	.202**	-.088	-.020	.215**	.220**
5	.022	.043	-.051	-.110	.017	-.014
6	.063	.029	-.092	-.061	.183*	.047
7	.231**	.252**	-.067	-.100	.395**	.317**
8	.095	.212**	-.096	-.050	-.218**	.154*
Total Score	.181*	.163*	-.120	-.069	.258**	.175*

** Correlation significant at 0.01
* Correlation significant at 0.05

Table 5.15: Correlation coefficients between PIIS subscales and total scores, and dimensions of the Family Coping Scale. A key to each subscale and dimension is given below.

KEY:

PIIS Subscale		FCOPES Subscale	
1	Burden of daily help	1	Acquiring social support
2	Emotional impact	2	Reframing
3	Social impact	3	Seeking spiritual support
4	Communication and understanding	4	Mobilising family support
5	Impact on personal future	5	Passive appraisal
6	Friends' reactions		
7	Parent / child relationship		
8	Global well-being		

FES PIIS	ss-1	ss-2	ss-3	ss-4	ss-5	ss-6	ss-7	ss-8	ss-9	ss-10
ss-1	.067	.012	**-.326****	**.253***	.097	-.093	-.035	-.176	-.032	**-.246***
ss-2	.060	.116	**-.275***	.228	.034	-.017	-.100	-.011	.069	**-.333****
ss-3	**.244***	.209	**-.385****	.191	.022	.048	.046	-.140	-.087	**-.306****
ss-4	.220	**.278***	**-.354****	.262	.058	.000	.130	-.158	-.037	-.178
ss-5	.104	-.005	-.207	.176	**.240***	-.049	.044	-.101	.056	-.182
ss-6	.085	**.275***	**-.294***	.035	-.095	-.133	**.237***	-.169	.094	-.198
ss-7	**.293***	**.299***	**-.309****	.043	-.022	.097	**.268***	-.054	.062	-.194
ss-8	.072	.055	-.124	-.065	.092	.058	.151	-.084	.134	-.031
Total Score	.213	.196	**-.417****	.223	.078	-.018	.105	-.174	.030	**-.292***

** Correlation significant at 0.01
* Correlation significant at 0.05

Table 5.16: Correlation coefficients between PIIS subscales and total scores, and subscales of the Family Environment Scale. A key to each subscale is given below.

KEY

PIIS Subscale	
1	Burden of daily help
2	Emotional impact
3	Social impact
4	Communication and understanding
5	Impact on personal future
6	Friends' reactions
7	Parent / child relationship
8	Global well-being

FES Subscale	
1	Cohesion
2	Expressiveness
3	Conflict
4	Independence
5	Achievement orientation
6	Intellectual-cultural orientation
7	Active-recreational orientation
8	Moral-religious emphasis
9	Organisation
10	Control

(5-3-iii-e) Discriminant validity – Evidence of discriminant validity is provided by non-significant correlations with specific subscales of the FCOPES (table 5.15) and the FES (table 5.16). No significant correlations were observed between FCOPES subscales seeking spiritual support, and mobilising family support. No significant correlations were observed between FES subscales intellectual-cultural orientation, moral religious emphasis and organisation. These results will be discussed further later.

(5-3-iii-f) Test-retest reliability – the PIIS was re-administered to a sample of 109 participants (45 Parkinson's children, 46 MS children, 18 stroke children) 2-4 weeks after initial administration, with a response rate of 65%. Table 5.17 displays correlation coefficients between first and second administrations for PIIS dimensions and total score. All are highly statistically significant.

Burden of daily help	.734**
Emotional impact	.737**
Social impact	.693**
Communication & understanding	.732**
Impact on personal future	.689**
Friends reactions	.651**
Parent / child relationship	.585**
Global well-being	.721**
PIIS Total Score	**.787****

** Correlation significant at 0.01

Table 5.17: Test-retest correlation coefficients for the PIIS

(5-3-iii-g) Visual analogue scale (VAS) – Evidence of validity for the VAS is provided in tables 5.18 to 5.21 by way of Spearman correlation coefficients.

	PIIS Visual Analogue Scale
Burden of daily help	.374**
Emotional impact	.351**
Social impact	.477**
Communication & understanding	.415**
Impact on personal future	.312**
Friends reactions	.417**
Parent / child relationship	.309**
Global well-being	.460**
PIIS Total Score	**.571****

** Correlation significant at 0.01

Table 5.18: Correlation coefficients between the PIIS visual analogue scale, subscales and total score

	PIIS Visual Analogue Scale
YQOL Total QoL Score (n=48)	.745**
EuroQol Visual Analogue Scale (n=116)	.541**

** Correlation significant at 0.01

Table 5.19: Correlation coefficients between the PIIS visual analogue scale, Youth Quality of Life Questionnaire total score, and EuroQol visual analogue scale

	PIIS Visual Analogue Scale
General quality of life	.720**
Self	.693**
Relationships	.703**
Environment	616**

** Correlation significant at 0.01

Table 5.20: Correlation coefficients between the PIIS visual analogue scale and Youth Quality of Life Questionnaire subscales.

	PIIS Visual Analogue Scale
Youth Quality of Life Questionnaire	.745**
Birleson Depression Inventory	-.581**
Parentification Questionnaire – Youth	-.471**
Rosenberg Self-Esteem Questionnaire	.528**
Social Support Scale for Children	.515**
Inventory of Parent & Peer Attachment	.600**
FCOPES	.185*
EUROQOL Visual Analogue Scale	.541**
Beck Depression Inventory	-.644**
Parentification Questionnaire - Adult	-.300**
Social Support Questionnaire	.342**
Family Environment Scale	.159*

** Correlation significant at 0.01
* Correlation significant at 0.05

Table 5.21: Correlation coefficients between the PIIS visual analogue scale and other administered instruments.

(5-3-iii-h) Analysis of dichotomous items (items 43-56). As dichotomous variables these items were not subject to any form of psychometric analysis. No problems were encountered in administration of these items, and their analysis is reported in chapters 6 & 7.

(5-4) Final revised instrument: based on the analysis performed here the PIIS-R is a 51 item instrument comprising of 37 items on a 5 point Likert scale with 14 dichotomous items and a visual analogue scale. The instrument for children of parents with Parkinson's aged 11-17 can be seen in appendix A-xi, and for those aged 18 and above in appendix A-xii. A scoring key is given in appendix A-xiii.

(5-5) Discussion

The hypotheses outlined at the beginning of this chapter are largely confirmed by the reported analyses. From the testing of a number of psychometric properties the revised PIIS appears to show both sound validity and reliability. These results are now discussed in further detail.

The validity of the revised instrument is demonstrated through a number of analyses. Content and face validity are supported by the key informant interviews, expert review and cognitive interview procedures reported in chapter 4, and results from the principal components analysis show the PIIS-R to have strong construct validity. The majority of factor loadings fall above the 0.55 level regarded as good, with a number above the 0.71 level regarded as excellent, and no item falls below the unacceptable level of 0.32 (Kline, 1994). The instrument shows good concurrent validity through correlations with existing validated instruments measuring similar or related constructs. The majority of instruments fall in the 0.40 to 0.60 range generally observed, with three above the 0.60 level, this representing a high degree of concurrent validity (McDowell & Newell, 1996). Importantly the most similar instrument administered, the Youth Quality of life instrument, demonstrates the strongest association with the PIIS-R at 0.67. There is also reasonable evidence of discriminant validity through non-significant correlations with the FES and FCOPES subscales with moral and spiritual emphases. The only spiritual question to be incorporated in the PIIS was removed at analysis due to the level of non-response (29%). Stronger evidence of discriminant validity is required in further administrations of the instrument, although current results are encouraging.

The reliability of the PIIS-R is supported by the two most commonly employed measures, namely internal consistency and test-retest reliability. Cronbach's alpha coefficients are above the recommended level of 0.70 (Scientific Advisory Committee of the Medical Outcomes Trust, 2002) in all but one sub-scale, indicating good internal consistency. The one subscale that falls below this figure that of *parent / child relationship*, remains above the 0.50 level suggested as sufficient by Helmstater (1964). Test-retest reliability for the instrument also appears strong. Total score correlations between first and second administration are high at 0.78. Test-retest correlations for PIIS-R subscales are also high in all but one subscale, again that of *parent / child relationship*, which falls just below the 0.6 level viewed as demonstrating substantial agreement (Andrews, 1976). It seems reasonable to speculate that this subscale might be particularly sensitive to fluctuating responses

due to the regular challenges children may face in their relationship with their parent, and particularly as their condition progresses. Reliability for the revised instrument is further supported by the low levels of missing values. Total score and subscale values fall at between 0.6% and 2.3%, in all bar one subscale, *friends reactions*, which, at 6.7 %, is still considerably lower than the 10% regarded as problematic (Bennet, 2001). The two items from this subscale that caused this high figure, items 12 and 13, were individually just above the figure recommended by Bennet (2001). The provision of a non-response option for these items is the likely cause for this, which as discussed below, has been adjusted in the final version of the questionnaire.

Visual analogue scales (VAS) have traditionally been used in the measurement of pain but are now being increasingly incorporated in the measurement of QoL (McDowell & Newell, 1996). The VAS incorporated in the PIIS was constructed on the traditional 10cm line (Seymour *et al.*, 1985) with a 10 point scale as recommended by McDowell & Newell (1996). The VAS shows good validity by way of correlations with both the PIIS and other instruments administered. Again the strongest correlations were with the most similar instruments, and the weakest correlations with those that provide discriminant validity for the instrument, namely the FES and FCOPES. There is some evidence that participants find them difficult to complete (Ferraz *et al.*, 1990), but no negative comments were received about the completion of the VAS in either pre-testing of the instrument or in the main survey administration.

When considering limitations it is recognised that the technique of factor / principal components analysis is controversial and has been widely criticised (e.g. Gross, 1996). A major criticism is that 'what you get out depends on what you put in', but this is hotly disputed by some (Kline, 1994). Debate exists on subject / variable ratios in PCA (Norman & Streiner, 2000). One guide to sample sizes states 50 as very poor, 100 as poor, 200 as fair, 300 as good, 500 as very good, and 1000 as excellent (Comrey & Lee, 1994). Other guides are far more conservative such as that of Kline (1994) who states 50 as the minimum, with 100 or more showing good reliability. Nestled between these two strongly opposing opinions is the 'rule of thumb' suggested by Norman & Streiner, (2000); five participants per variable assuming a minimum of 100 participants. The sample size of 169 incorporated in this study therefore appears adequate. One of the key criteria of the technique is that a 'good' PCA makes sense, and a poor one fails to do so, and interpretability of results

reported here are considered adequate. Sound validity and reliability serve to reinforce this. It is, however, recognised that the instrument may benefit from being administered to larger samples.

Providing a non-response or neutral response option is controversial, with some promoting their use, others actively dissuading them (Fox, 1996). The reasons for this are relatively clear from both sides. Legitimising non response can lead to missing data, although some studies have shown increased respondent satisfaction when provided with neutral options (e.g. Heller & Rife 1987). Further research has shown that when not provided with a 'don't know option' 25% of participants gave a response rather than leaving the item blank (Shuman & Presser, 1981). Whilst overcoming the problem of missing data to an extent, there is clearly a strong element of response error inherent in this approach. To overcome this as is best possible the PIIS-R provides the response option of 'never or not applicable' and is scored or reverse-scored as appropriate. Such an option has previously been employed by Powell *et al.* (1998).

Finally, analysis of the psychometric properties of the PIIS-R must continue with further administration, preferably in larger samples. One factor in particular, *parent / child relationship*, warrants further attention due to its relatively weak reliability in comparison to other subscales within the revised instrument. It is also recognised that cross-sectional studies, such as that reported here, do not allow for a full psychometric assessment, Longitudinal data will provide the opportunity for further properties, such as predictive validity and sensitivity to change, to be assessed.

(5-6) Chapter Summary – The final survey instrument of 51 items has been subject to intensive pre-testing and psychometric analysis. As an instrument some two thirds of the size at its conception the PIIS-R has evolved into a scientifically sound and respondent friendly tool with which to measure the impact of parental illness.

Chapter 6: Children of Parents with Parkinson's Disease

(6-1) Introduction: As discussed in chapter 1 the only two studies previously conducted with children of parents with PD highlight the need for further research with this group (Grimshaw, 1991; Schrag *et al.*, 2004). Both reports underline issues of social and emotional well-being, reduced independence, and fears for the future when adolescent and adult children are faced with parental Parkinson's. The study of Schrag *et al.* (2004) also highlights the deleterious effects on adolescent and adult children's QoL as their parent's condition advances over time, as well as differences by age and gender. Studies in other parental conditions have also suggested that the gender of the affected parent may be a significant factor (i.e. Steck *et al.*, 2001). This chapter aims to build on previous findings by considering aspects not previously assessed, as well as confirming those that have.

(6-1-i) Aims and hypotheses: The aims of this phase of the research were therefore fourfold:

1. To identify the impact of parental Parkinson's on adolescent and adult children's QoL as measured by the revised Parental Illness Impact Scale (PIIS-R).
2. Assess the impact of parental Parkinson's on children's psychosocial well-being.
3. Identify sociodemographic variables implicated in response to parental PD.
4. Examine relationships between child and parent well-being.

Specifically it is hypothesised that:

c) Children of PWP who remain in the family home will report significantly inferior QoL and psychosocial well-being than children who do not live with their affected parent.
d) QoL and psychosocial well-being will differ by gender of child, and gender of affected parent.
e) QoL will be significantly related to sociodemographic variables, i.e. children's current age, age at their parent's diagnosis, SES, and their proximity to the parental home.
f) There will be a significant relationship between children's QoL and parental well-being, i.e. QoL, ability to perform activities of daily living, mental health, and disease duration.

(6-2) Methods:

(6-2-i) Sample Recruitment: Participants were recruited as reported in chapter 5.

(6-2-ii) Materials: In order to identify possible relationships between children's response to parental PD and the well-being of both the affected and non-affected parent, all family members were asked to complete questionnaires as follows:

(6-2-ii-a) ***Questionnaire battery for adolescent children age 11-17:*** Participants aged 11 to 17 were asked to complete a battery of questionnaires as detailed in chapter 5.

(6-2-ii-b) ***Questionnaire battery for adult children age 18 and above*****:** Participants aged 18 and above were asked to complete a battery of questionnaires as detailed in chapter 5.

(6-2-ii-c) ***Questionnaires administered to parent with PD:*** Parents with PD were asked to complete the following questionnaires:

- ***EUROQoL-5D*** (EUROQOL GROUP, 1990): As described in chapter 5. The instrument has been widely used in different patient populations including PD (e.g. Wade *et al.*, 2003; Schrag *et al.*, 2000a, b), Stroke (e.g. Sulch *et al.*, 2002; Dorman *et al.*, 1998), and MS (e.g. Forbes *et al.*, 1999; Myers *et al.*, 2003).

- ***Self-administered Schwabb & England Measure of Disability*** (Schwabb & England, 1969): A self-administered 10-point disability scale with 10 indicating complete independence and 0 indicating complete dependence. Agreement between clinician and patient ratings in a previously studied sample of patients with PD has been found to be high at .82 (*unpublished*). This instrument was administered in conjunction with the SRBI (detailed below) as a means of a preliminary validation of the SRBI in PD patients. Results are reported in a later section of this chapter.

- ***Self-Report Barthel Index*** (SRBI) (Gompertz, *et al*, 1994): A 10 item multiple-choice questionnaire, developed as a self administered version of the Barthel Index (Mahoney & Barthel, 1965). The original Barthel Index is regarded as the most popular measure of competency in activities of daily living, and has been recommended as a standard measure of disability (Wade & Collins, 1988). The self-report version of the instrument has been validated in both PWMS (Hobart *et al*, 1996) and stroke patients (Gompertz *et al*, 1994).

- ***Beck Depression Inventory*** (BDI): As described in chapter 5.

(6-2-ii-d) ***Questionnaires administered to non-affected parent:***

- ***EUROQoL-5D*** As described in chapter 5.

(6-2-ii-e) ***Family assessment of socio-economic status:*** In addition to individual questionnaire booklets, as an assessment of socio-economic status, each family completed the National Statistics Socio-Economic Classification (NS-SEC) Self-Coded Method questionnaire (appendix 1)

(6-2-ii-f) ***Assessment of socio-demographic variables:*** All family members were asked a series of sociodemographic questions at the beginning of their questionnaire battery. For adolescent and adult children these can be viewed in appendix 2, for the affected parent in appendix 3, and for the non-affected parent in appendix 4.

(6-2-iii) Statistical analysis: Data was entered into SPSS and coded in order to maintain confidentiality. Sub-scale and summary scores for established instruments were calculated according to respective scoring algorithms. Student *t* and Mann Whitney tests were performed to compare means between groups. Analysis of dichotomous variables was calculated using chi square analysis. Pearson and Spearman correlation coefficients were calculated to test associations between sociodemographic data with QoL. Data were checked for presence of outliers and normality of distribution prior to statistical analysis. Distribution of data was analysed using Kolmogorov-Smirnov and Shapiro-Wilk (for sample size less than 30) tests of normality.

(6-3) Results: The following section firstly reports analyses of QoL and psychosocial well-being in children of parents with PD, followed by analyses of sociodemographic variables, and finally considers relationships between parental well-being and that of the child.

(6-3-i) Description of Sample: The total sample consisted of 150 participants. Of these, 79 were children of parents with PD, 41 were the patients themselves, and 30 were their spouse or carer. Sociodemographic data are presented in tables 6.1, 6.2 and 6.3.

Sample size	79
Gender M:F%	40.5% : 59.5%
Mean age (y)	27.22 (*SD* 9.80)
Mean age of child at onset of parent's PD (y)	16.46 (*SD* 9.67)
Mean duration of parent's PD (y)	10.56 (*SD* 6.15)
% only child	7.6%
% living in parental home	30.4%
Affected parent	Mother 47.4%, father 52.6%

SD = standard deviation; y = years

Table 6.1: Sociodemographic characteristics of children of parents with Parkinson's.

Sample size	41
Gender M:F%	48.8% : 51.2%
Mean age (y)	57.22 (*SD* 8.84)

SD = standard deviation; y = years

Table 6.2: Sociodemographic characteristics of parent with Parkinson's.

Sample size	30
Gender M:F%	30.0% : 70.0%
Mean age (y)	56.30 (*SD* 8.318)

SD = standard deviation; y = years

Table 6.3: Sociodemographic characteristics of non-affected parent.

(6-3-ii) Analysis of QoL:

Table 6.4 displays PIIS-R mean, range and standard deviations for subscale and total scores for children of parents with PD.

	Mean	Range	Standard deviation
Burden of daily help	31.82	8-40	6.60
Emotional impact	15.26	4-20	3.23
Social impact	26.30	6-30	4.03
Communication & understanding	24.91	7-35	5.16
Impact on personal future	9.98	3-15	2.70
Friends' reactions	13.17	3-15	2.39
Parent / child relationship	10.63	3-15	2.47
Global well-being	10.02	3-15	2.54
PIIS total score	**158.83**	**37-185**	**21.41**

Table 6.4: Mean and standard deviation PIIS-R scores for children of parents with PD

Table 6.5 displays comparisons of PIIS-R subscale and total scores between those children who remain in the parental home and those that do not. Children who remain in the parental home report a significantly heightened burden of daily help than children who have left home (t=-4.59, p<0.00). Similarly, with regard to friends' reactions, children who still reside with their parent with PD report significantly greater difficulty than those that have left the family home (t=-2.81, p<0.01).

	Mean			
	At parental Home	Not at parental home	*t*	*P*
Burden of daily help	26.79	34.16	-4.59	.000
Emotional impact	14.79	15.49	-.888	.379
Social impact	26.12	26.43	-.296	.769
Communication & understanding	24.95	24.98	-.023	.982
Impact on personal future	10.62	9.78	1.22	.226
Friends' reactions	12.05	13.07	-2.81	**.008**
Parent / child relationship	10.83	10.54	.440	.662
Global well-being	10.34	9.92	.671	.506
PIIS total score	**153.49**	**161.65**	**-1.57**	**.138**

Table 6.5: Comparison of mean PIIS-R subscale and total scores for Parkinson's children living within the parental home and those not in the parental home

Table 6.6 shows comparisons of PIIS-R subscale and total scores by gender. Female participants report significantly worsened communication and understanding with their parent with PD than do male participants (t=2.22, p<0.05). Females also report lower total QoL scores than males, although this just fails to reach statistical significance (t=1.82, p>0.05). The trend of females reporting inferior QoL is maintained across all domains.

	Mean			
	Male	Female	*t*	*p*
Burden of daily help	32.90	31.25	1.15	.253
Emotional impact	15.62	15.04	.769	.444
Social impact	26.96	25.91	1.21	.229
Communication & understanding	26.46	23.96	2.22	.029
Impact on personal future	10.34	9.82	.793	.432
Friends' reactions	13.35	13.10	.496	.621
Parent / child relationship	11.03	10.36	1.18	.242
Global well-being	10.43	9.79	1.10	.272
PIIS total score	**164.04**	**155.86**	**1.82**	**.071**

Table 6.6: Comparison of mean PIIS-R subscale and total scores for Parkinson's children by gender

No significant differences were observed by gender of affected on PIIS-R subscale and total scores.

Percentage scores from PIIS-R dichotomous items 43-56 are presented in table 6.7. Results worthy of note include 53.8% feeling uncertain as to what will happen in the future to their unwell parent (item 44), 52.5% would find training in how to give practical care helpful (item 51), and 61% think more assistance should be provided by local services (item 55).

PIIS Item	% Yes	% No
43 – Have enough information	62.5	37.5
44 – Know enough about what will happen in the future to unwell parent	46.3	53.8
45 – Rely solely on parents for information about parent's illness	61.3	38.8
46 – Have somebody to talk to about parent's illness if want to	70.4	29.6
47 – Have support from friends and family	81.3	18.7
48 – Have ways to cope with any feelings of anger	74.5	25.5
49 – Parent talks about their illness	77.5	22.5
50 – Would help to have contact with people in similar circumstances	43.6	56.4
51 – Would help to have training in giving practical care	52.5	47.5
52 – Would be helpful to have opportunity for counselling	35.0	65.0
53 – Would help to have counselling as family	21.5	78.5
54 – Outside help available to help care for parent with PD	40.8	59.2
55 – Think more help (e.g. meals on wheels, physiotherapy) should be provided by services	61.0	39.0
56 – Would help to be able to talk to local services about help provided to parent	40.5	59.5

Table 6.7: Percentage scores for PIIS-R items 43-45

Comparisons between those who remain in the parental home and those who do not for items 43-56 are presented in table 6.8. The sole item to meet statistical significance is item 45 (x^2 = 4.41, p<0.05), with significantly more children living at home relying solely on their parents for information about PD. Three other items worthy of note just fail to meet significance. For item 44 considerably more children within the family home report knowing enough about what will happen to their parent in the future (x^2 = 2.84, p>0.05). For item 53 considerably more children not living within the parental home would find it helpful to have the opportunity for counselling as a family (x^2 = 3.28, p>0.05). For item 56 considerably more children not living within the parental home would find it helpful to talk to local services about help provided for their parent (x^2 = 2.73, p>0.05).

PIIS Item	In parental home		Left Parental home		x^2	df	p
	% Yes	% No	% Yes	% No			
43 – Have enough information	69.6	30.4	63.6	36.4	.252	1	.616
44 – Know enough about what will happen in the future to unwell parent	60.9	39.1	40.0	60.0	2.84	1	.092
45 – Rely solely on parents for information about parent's illness	78.3	21.7	52.7	47.3	4.41	1	**.036***
46 – Have somebody to talk to about parent's illness if want to	66.7	33.3	72.7	27.3	.297	1	.586
47 – Have support from friends and family	87.0	13.0	80.0	20.0	.533	1	.465
48 – Have ways to cope with any feelings of anger	75.0	25.0	75.8	24.2	.003	1	.958
49 – Parent talks about their illness	73.9	26.1	78.2	21.8	.166	1	.683
50 – Would help to have contact with people in similar circumstances	47.8	52.2	41.5	58.5	.261	1	.610
51 – Would help to have training in giving practical care	62.5	37.5	48.1	51.9	1.37	1	.241
52 – Would be helpful to have opportunity for counselling	41.7	58.3	31.5	68.5	.762	1	.383
53 – Would help to have counselling as family	8.3	91.7	26.4	73.6	3.28	1	.070
54 – Outside help available to help care for parent with PD	39.1	60.9	43.1	56.9	.105	1	.746
55 – Think more help (e.g. meals on wheels, physiotherapy) should be provided by services	60.9	39.1	61.5	38.5	.003	1	.956
56 – Would help to be able to talk to local services about help provided to parent	26.1	73.9	46.3	53.7	2.73	1	.098

* p < 0.05

Table 6.8: PIIS-R items 43-56: Percentage scores are given between those within the parental and those not, with chi-squared statistics

(6-3-iii) Analysis of psychosocial variables:

Table 6.9 displays comparisons between children living in the parental home compared to those who do not from psychosocial instruments administered. Analysis of instruments administered solely to 11-17 year olds was not possible as all resided with their parents. No significant results were observed, although the trend of those remaining in the parental home reporting inferior psychosocial well-being is maintained in all domains apart from self-esteem.

	Mean			
	At parental Home	Not at parental Home	*t*	*p*
Rosenberg Self-Esteem Questionnaire	32.33	30.90	.954	.346
Beck Depression Inventory	6.81	5.76	.480	.638
Parentification Questionnaire - Adult	17.09	15.51	.780	.446
Social Support Questionnaire	29.10	32.29	-1.63	.130

Table 6.9: Comparison of mean total scores for Parkinson's children living in the parental home and those not

Table 6.10 displays comparisons between genders from psychosocial instruments administered. Females report lower self esteem (t=2.29, p<0.05) and higher depression scores (t=-2.62, p<0.05) than males. When focusing on social support, adolescent boys report lower scores than adolescent girls although this fails to reach significance (z=1.934, p>0.05).

	Mean			
	Male	Female	*t / z*	*p*
Birleson Depression Inventory	8.11	4.71	-1.177	.239
Parentification Questionnaire – Youth	4.22	3.14	-1.020	.308
Rosenberg Self-Esteem Questionnaire	33.12	30.10	2.29	**.018**
Social Support Scale for Children	80.00	89.50	1.934	.053
Inventory of Parent & Peer Attachment	115.44	124.28	-1.634	.100
Beck Depression Inventory	3.60	7.36	-2.62	**.011**
Parentification Questionnaire - Adult	14.04	16.80	-1.758	.084
Social Support Questionnaire	32.36	31.43	.778	.440

Table 6.10: Comparison of psychosocial scores for Parkinson's children by gender

(6-3-iv) Predictive factors:

When self-esteem, family coping style, mental health, parentification and social support were considered by regression analysis it provided evidence that for adult children aged 18 and above, the sole predictor of QoL was mental health (f = 11.13, p <0.00). Regression analysis for adolescent children aged 11-17 was not possible due to sample size. It was therefore considered appropriate to examine levels of reported depression further in both age groups.

(6-3-v) Levels of self-reported depression:

12.5% of adolescent and 17.7% of adult children reported depression as measured by the Birleson Depression Inventory and Beck Depression inventory respectively. Breaking down adult depression scores into the standard BDI categories reveals 14.3% reporting mild symptoms, 3.2% reporting moderate symptoms and a further 3.2% have severe depression.

(6-3-vi) Analysis by socio-demographic variables:

Correlations between the PIIS-R, the child's current age, and their age at parent's diagnosis are presented in table 6.11. Current age correlated positively with burden of daily help (r=.229, p<0.05) and friends reactions (r_s =.346, p<.001), and correlated negatively with impact on personal future (r=-.332, p<0.01). Child's age at diagnosis correlated negatively with impact on personal future (r=-.372, p<0.01) and positively with friends reactions (r_s =.242, p<.001).

	Child's current age	Childs age at diagnosis
Burden of daily help	**.229***	.208
Emotional impact	.044	.211
Social impact	-.149	-.128
Communication & understanding	-.070	.098
Impact on personal future	**-.332****	**-.372****
Friends' reactions	**.346****	**.242****
Parent / child relationship	-.070	.124
Global well-being	-.170	-.128
PIIS total score	**-.010**	**.085**

** Correlation significant at 0.01
* Correlation significant at 0.05

Table 6.11: Correlations between PIIS-R subscales and total score, and parental disease duration, child's current age, and age at diagnosis of parent's PD

Table 6.12 displays correlations between the PIIS-R and further socio-demographic variables. PIIS subscale friends' reactions correlates negatively with socioeconomic classification (r=-.402, p<0.01). Distance from parents home correlates positively with PIIS-R total score (r=.356, p<0.01), and subscales burden of daily help (r=.457, p<0.01), emotional impact (r=.296, p<0.01), social impact (.270, p<0.05), and friends' reactions (r=.379, p<0.01). PIIS-R subscale communication and understanding correlates positively with number of siblings (r=.280, p0.05).

	Socioeconomic classification	Distance from parents home	Number of siblings
Burden of daily help	-.194	**.547****	-.022
Emotional impact	.223	**.296****	.186
Social impact	-.030	**.270***	.136
Communication & understanding	.048	.195	**.280***
Impact on personal future	.207	-.118	.069
Friends' reactions	**-.402****	**.379****	.145
Parent / child relationship	-.034	.126	-.035
Global well-being	.204	.003	.136
PIIS total score	**.004**	**.356****	**.155**

** Correlation significant at 0.01
* Correlation significant at 0.05

Table 6.12: Correlations between PIIS-R subscales and total score, and socioeconomic classification, proximity to the parental home and number of siblings

(6-3-vii) Correlations with parent variables:

(6-3-vi-a) Preliminary validation of Self-Report Barthel Index (SRBI) in Parkinson's patients:

As part of this study, an attempt was made to make a preliminary assessment of the validity of the SRBI in PD patients, in order to be able to make comparisons with PWMS and stroke sufferers (reported in chapter 7). The SRBI was therefore administered in conjunction with the Schwab & England scale and the PDQ-39 (Peto, *et al*, 1995). Results are presented in table 6.13.

	Self-Report Barthel Index
Schwab & England Scale	.561**
PDQ39 ADL Dimension	-.538**
PDQ39 Mobility Dimension	-.493**
PDQ-39 single index score	-.361*

** Correlation significant at 0.01
* Correlation significant at 0.05

Table 6.13: Correlations between the SRBI and the Schwab & England Scale, and dimensions of the PDQ39

Significant correlations were observed between the SRBI and the Schwab & England Scale (r_s .561, p<0.01), the ADL dimension of the PDQ39 (r_s -.538, p<0.01) and the mobility dimension of the PDQ-39 (r_s -.493, p<0.01). A weaker correlation was established with PDQ39 single-index score (r_s -.361, p<0.05). These results suggest the ADL is a reasonable indicator of functional disability in PD patients.

(6-3-vi-b) Correlations with affected parent's ADL, QoL, mental health and disease duration:

Table 6.14 displays correlations between the PIIS-R and parent variables. Significant positive correlations are observed between the parent with Parkinson's ADL score and PIIS-R subscales social impact (r=.338, p<0.01), and impact on personal future (r=.308, p<0.05), whilst PIIS-R total score and parent ADL score just fails to meet significance (r=.273, p>0.05). The correlation between parent's level of depression and PIIS-R subscale emotional impact just fails to meet significance (r=-.270, p>0.05). Parental disease duration correlated negatively with communication and understanding (r=-.234, p<0.05), and parent / child relationship (r=-.307, p<0.01).

	Parent's ADL score	Parent's QoL score	Parent's level of depression	Parents disease duration
Burden of daily help	.150	-.096	.053	.003
Emotional impact	.179	-.064	-.270	-.179
Social impact	**.338****	-.156	.011	-.072
Communication & understanding	.083	-.067	-.160	**-.234***
Impact on personal future	**.308***	-.012	-.229	.030
Friends reactions	-.012	-.086	.004	.100
Parent / child relationship	.132	-.027	.109	**-.307****
Global well-being	-.015	-.152	.167	-.115
PIIS total score	**.273**	**-.128**	**-.069**	**-.144**

** Correlation significant at 0.01
* Correlation significant at 0.05

Table 6.14: Correlations between PIIS-R subscales and total score, and the affected parent's ADL score QoL level of depression, and disease duration.

(6-3-vi-c) Correlations with unaffected parent's QoL:

There were no significant correlations between the QoL of the unaffected parent and the QoL of the child.

(6-4) Discussion

The hypotheses outlined at the beginning of this chapter are only partially confirmed by the results. The hypothesis that children who remain in the family home would report significantly inferior QoL and psychosocial well-being than children who do not live with their affected parent was confirmed in only two components of QoL as measured by the PIIS-R. The hypothesis that QoL and psychosocial well-being would differ by gender of child and gender of affected parent was only partially accepted, with differences only seen in specific aspects between male and female children. The hypothesis that QoL would be significantly related to sociodemographic variables, i.e. children's current age, age at their parent's diagnosis, SES, and their proximity to the parental home, was partially confirmed through a number of significant correlations with specific components of QoL. The final hypothesis that there would be a significant relationship between children's QoL and parental well-being was only partially confirmed by associations between specific components of child QoL and parents' ability to perform daily activities, and disease duration. These findings are now discussed in further detail.

Previous research into children of parents with Parkinson's disease has been limited to two studies (Grimshaw, 1991; Schrag *et al.*, 2004). The current study builds on and provides further insight into the impact of parental PD. Many of the findings of Schrag *et al.* (2004) are confirmed by this data, but an important distinction needs to be made. The study of Schrag *et al.* analysed data by age group, i.e. those aged 12-24, and those aged 25 and above. Much of the current data was analysed based on grouping children into those who lived in the parental home and those who do not, with the hypothesis that the former would be more affected. This was only confirmed in only two components of QoL. Children living at home reported a significantly heightened sense of burden in relation to the help they give, and also greater problems in interactions with friends as measured by the PIIS-R. Both of these results have important implications for service providers. In addressing the perceived burden of daily help only 40% of families had access to support from local services, whilst approximately 60% thought more support should be provided. The finding that children have difficulties with friends may well be addressed by providing improved levels of information, thereby allowing them to feel better informed and more comfortable with their parent's Parkinson's.

Further analysis of the dichotomous variables of the PIIS-R showed more than a third of children reported insufficient information about PD, and this increased to approximately 55% not knowing enough about what will happen in the future to their parent with PD. Both of these findings are consistent with previous results (Grimshaw, 1991; Schrag *et al.*, 2004). There is, however, one slightly counterintuitive result in relation to the latter. When comparing results between those children in the parental home with those who have left, of the former over 60% report knowing enough about what will happen in the future to their parent with PD. This statistic falls to 40% for their counterparts who have left home. The early qualitative work reported in chapter 4 may provide a useful insight into this. A number of the children interviewed stated that they felt they had enough information for the time being, but that as they got older they may well seek further knowledge about their parent's Parkinson's. This also has important implications for services and future interventions in recognising that children should be allowed to access information at a time that is comfortable and appropriate for them. The key is to have such information and support available as and when required.

Although no significant differences were found based on the gender of the affected parent, differences were evident between male and female children. With regard to QoL differences in total scores as measured by the PIIS-R just fail to meet significance, although there is a consistent trend of females reporting lower scores than males on all subscales. One subscale does however stand out; females reported significantly greater difficulties than males with communication and understanding their parent with Parkinson's. Research has shown that females rely emotionally on their parents significantly more than do males (Moore, 1987), as well as remaining closer to their parents (Frank *et al.*, 1990; Paterson *et al.*, 1994). It seems likely therefore that females in this study report far greater difficulties with emotional adjustment due to their greater dependence on the parent than males.

In comparing psychosocial variables females reported significantly lower self-esteem and greater levels of depression than males, and both of these results replicate the findings of Schrag *et al.* (2004). The current, however study builds on this previous work in assessing psychosocial variables not previously assessed children of PWP, and results do not entirely follow the pattern established with QoL, self-esteem and depression scores. Adult females do report higher levels of parentification, although this just fails to meet significance. Adolescent males, however, report less positive

attachment and lower levels of social support, although again these differences are not statistically significant.

The finding that mental health is the single most important predictor of QoL for adult children of parents with Parkinson's highlights the emotional strain on this group, and the importance of its recognition and treatment. Depression, however, commonly goes undiagnosed in both adults (Freeling *et al.*, 1985) and adolescents (Kramer & Garralda, 2000). In the current sample 17.7% of the total sample reported depressive symptoms. Broken down further, 12.5% of adolescent children and 17.7% of adult children reported mild to severe depression. Both these figures are approximately twice the levels estimated in the normal population for adolescents (Hazell, 2002; Son & Kirchner, 2001) and adults (Singleton *et al.*, 2001), and very much reflect the levels of depression in the study of Schrag *et al.* (2004) where approximately 20% of children reported mild-moderate depression. The implications of this are addressed in chapter 7.

Analysis was also undertaken of socio-demographic variables. Significant correlations were established with the age of the child and the child's age at diagnosis in certain aspects of QoL as measured by the PIIS-R. The perceived impact on personal future increases as children get older. This is perhaps unsurprising since, with increasing age, children may become increasingly aware and realistic about their parent's condition. They are also better equipped educationally and emotionally to deal with the realistic prospects of their parent's condition (Lewandowski, 1992). This again helps to explain the finding that 60% of children who have left home, against 40% who have not, feel they do not know enough about what will happen to their parent in the future. It seems clear that from both the qualitative and quantitative data, that older children feel a need to become better informed as they become older and their parent's Parkinson's progresses.

The highly significant correlations with PIIS-R total score and specific subscales, and 'distance from parents home' serves to highlight further the trend between those children within the parental home and those not. Unsurprisingly the two most significant correlations with proximity to the parental home mirror the two significant comparisons, i.e. burden of daily help, and friends' reactions. PIIS-R scores increase the further the child lives from their parent highlighting the impact of having to live with the emotional and practical consequences of parental Parkinson's on a daily basis. The sole correlation observed with socioeconomic classification was with the

subscale 'friends' reactions', i.e. problems with peer relationships increase significantly with lower SES. SES has consistently been linked with positive well-being in both adults (Alder *et al.*, 1994) and children (Bradley & Corwyn, 2002), and research has also shown that inferior SES in childhood and adolescence is related to poor psychosocial functioning in later life (Harper *et al.*, 2002). Interpreting this in relation to data presented in this thesis will be discussed further in the following chapter.

Correlations were also calculated between the PIIS-R and the affected parents ADL score, QoL, level of depression, and disease duration. Significant correlations were observed with two PIIS-R subscales and the parent's ADL score. A highly significant correlation was seen between social impact and a significant but weaker correlation with PIIS subscale impact on personal future. The former might reflect the limitations Parkinson's places on families to function socially as reported in previous studies (Wallhagen & Brod 1997; Whetten-Goldstein *et al.*, 1997), and the limitations it also places on the child's opportunities to interact with their peer group (Grimshaw, 1991). One could speculate that the latter appears to reflect the child's concern for their parent as their ability to function in basic self-management tasks deteriorates. Given that this will inevitably worsen, it seems natural this would lead the child to consider the possibilities of taking on a caring role in the future, how this might affect their independence, and lead to inevitable concerns about the future. The effects of the progressive nature of PD and its impact on the child are further highlighted by significant correlations with parental disease duration. Both communication and understanding, and the parent / child relationship appear to deteriorate over time. No correlations were observed with the unaffected parent's QoL. This may warrant further investigation in, for example, assessing if the child's QoL is linked to the unaffected parent's mental health.

Finally, the preliminary validation of the SRBI in Parkinson's patients was performed to provide a uniformity of results when making comparisons with MS and stroke reported in chapter 7. Correlations with existing measures demonstrate acceptable concurrent validity, and suggest that the SRBI is a valid tool for use with Parkinson's patients, although further validation in a larger sample is required

(6-5) Chapter summary: Data presented in this chapter serve to reinforce and expand on the previous limited research findings. Results highlight a limited number of areas of concern for children living with their affected parent, the availability and

accessibility of information, issues surrounding mental health, differences by gender, and modest associations between certain aspects of parental well-being. The following chapter will develop this further in assessing the impact of parental illness in children of PWMS and stroke patients, and making comparisons with the sample reported here.

Chapter 7: Comparing Children of Parents with Parkinson's, Multiple Sclerosis and Stroke

(7-1) Introduction: The aims of the study reported in this chapter were to compare the children of parents with Parkinson's reported in chapter 6, with children of another chronic neurological condition, MS, and an acute neurological condition, stroke. Chapter 1 reviewed current research conducted with children of PWMS, and the first two studies of the impact of parental stroke (Visser-Meily *et al.*, 2005a;b). The study reported in this chapter aims to extend this previous research in assessing a number of previously unreported variables, as well as making a first comparison between the three groups.

(7-1) Aims and hypotheses: The aims of this phase of the research were as follows:

1. To assess and compare the QoL of children across the three parental conditions as measured by the revised Parental Illness Impact Scale (PIIS-R).
2. Assess and compare the psychosocial well-being of children across the three parental conditions.
3. Identify and compare sociodemographic variables implicated in children's response to each of the three parental conditions.
4. Examine relationships between child QoL and parental well-being across the three conditions.

Specifically it is hypothesised that:

g) There will be significant differences in QoL between children of parents with PD, MS and stroke.
h) There will be significant differences in psychosocial well-being between children of parents with PD, MS and stroke.
i) There will be differences in the sociodemographic variables implicated in children's response to each parental condition.
j) There will be differences in relationships between child QoL and parental well-being implicated in children's response to each parental condition.

(7-2) Methods:

(7-2-i) Sample Recruitment: The sample was recruited as described in chapter 5.

(7-2-ii) Materials

(7-2-ii-a) ***Questionnaire battery for adolescent children age 11-17:*** Participants aged 11 to 17 were asked to complete a battery of questionnaires as detailed in chapters 5 and 6.

(7-2-ii-b) ***Questionnaire battery for adult children age 18 and above*****:** Participants aged 18 and above were asked to complete a battery of questionnaires as detailed in chapters 5 and 6.

(7-2-ii-c) ***Questionnaires administered to PWMS and stroke patients:*** PWMS and stroke patients were asked to complete questionnaires for the affected parent as detailed in chapter 6, with the exception of the Schwab and England measure of disability.

(7-2-ii-d) ***Questionnaires administered to non-affected parent:*** The non affected parent was asked to complete the EUROQOL-5D as detailed in chapter 5

(7-2-ii-e) ***Family assessment of socio-economic status:*** In addition to individual questionnaire booklets, as an assessment of socio-economic status, each family completed the National Statistics Socio-Economic Classification (NS-SEC) Self-Coded Method questionnaire as described in chapter 6.

(7-2-ii-f) ***Assessment of socio-demographic variables:*** All family members were asked to complete a cover sheet detailing sociodemographic information as described in chapter 6.

(7-2-iii) Statistical analysis: Data was entered into SPSS and coded in order to maintain confidentiality. Sub-scale and summary scores for established instruments were calculated according to respective scoring algorithms. ANOVA and Kruskal Wallis statistics were calculated to compare means between groups, with Tukey pairwise comparisons calculated to identify significant differences and adjust for multiple comparisons. Student *t* and Mann Whitney tests were performed to compare

means between groups. Pearson and Spearman correlation coefficients were calculated to analyse continuous variables. Data were checked for presence of outliers and normality of distribution prior to statistical analysis. Distribution of data was analysed using Kolmogorov-Smirnov and Shapiro-Wilk (for sample size less than 30) tests of normality.

(7-3) Results: The following section firstly reports comparisons of QoL and psychosocial variables between children of parents with PD, PWMS and stroke patients, and follows with analysis of sociodemographic variables. Analyses then focus specifically on data relating to numbers of siblings in the families of children who participated, and close with relationships between the well-being of the parent and that of the child.

(7-3-i) Description of Sample: The total sample consisted of 327 participants. Of these, 79 were children of parents with PD, 41 the affected parent, and 30 the unaffected parent reported in chapter 6. Sociodemographic characteristics of children of PWMS are given in table 7.1, children of stroke patients in table 7.2, and their affected and unaffected parent in tables 7.3 and 7.4.

Sample size	62
Gender M:F%	45.2% : 54.8%
Mean age (y)	21.37 (*SD* 8.18)
Mean age of children at diagnosis (y)	9.65 (*SD* 8.27)
Mean duration of parent's MS (y)	11.65 (*SD* 7.62)
% only child	11.3%
% living in parental home	50%
Affected parent	Mother 73.8%, father 26.2%

SD = standard deviation; y = years

Table 7.1: Sociodemographic characteristics of children of PWMS

Sample size	26
Gender M:F%	57.7% : 42.3%
Mean age (y)	22.81 (*SD* 9.39)
Mean age of children at diagnosis (y)	17.00 (*SD* 9.92)
Mean duration since parent's stroke (y)	5.28 (*SD* 4.71)
% only child	11.5%
% living in parental home	57.7%
Affected parent	Mother 38.5%, father 61.5%

SD = standard deviation; y = years

Table 7.2: Sociodemographic characteristics of children of stroke patients

	MS	**Stroke**
Sample size	36	14
Gender M:F%	19.4% : 80.6%	57.1% : 42.9%
Mean age (y)	49.64 (*SD* 10.65)	49.14 (*SD* 9.78)

SD = standard deviation; y = years

Table 7.3: Sociodemographic characteristics of PWMS and stroke patients

	MS	**Stroke**
Sample size	26	13
Gender M:F%	70.4% : 29.6%	23.1% : 76.9%
Mean age (y)	53.08 (*SD* 8.36)	47.92 (*SD* 7.72)

SD = standard deviation; y = years

Table 7.4: Sociodemographic characteristics of spouses / carers of PWMS and stroke patients

(7-3-ii) Parental illness group comparisons of child QoL: Tables 7.5 and 7.6 report comparisons of QoL as calculated by the PIIS-R between children of parents with PD, PWMS and stroke patients. Results of ANOVA presented in table 5 show significant differences in two subscales of the PIIS; communication and understanding (f=3.11, p<0.05), and global well-being (f=3.76, p<0.05). PIIS total score just fails to meet significance (f=2.74, p>0.05). Tukey pairwise comparisons reveal statistically significant differences between children of parents with Parkinson's and children of stroke patients in communication and understanding (p<0.05), and global well-being (p<0.05).

	df	*f*	*p*
Burden of daily help	2, 166	1.529	.220
Emotional impact	2, 166	0.800	.451
Social impact	2, 166	1.612	.203
Communication & understanding	2, 166	3.11	**.047**
Impact on personal future	2, 166	2.089	.127
Friends' reactions	2, 166	0.694	.501
Parent / child relationship	2, 166	1.851	.160
Global well-being	2, 166	3.764	**.025**
PIIS total score	2, 166	2.473	.087

Table 7.5: Analysis of variance of PIIS-R

Table 7.6 displays mean PIIS-R scores by disease group, and confirm results presented in table 7.5. Whilst only two subscales show significant differences, the trend observed is fairly uniform. Children of stroke patients report the lowest QoL scores, followed by children of PWMS, and children of parents with PD reporting the highest scores. The two exceptions to this are children of PWMS reporting the greatest emotional impact and children of parents with Parkinson's reporting the greatest concerns for impact on personal future.

	PD n=81	MS n=62	Stroke n=26
Burden of daily help	31.78	30.92	29.24
Emotional impact	15.23	14.53	14.92
Social impact	26.28	25.25	24.85
Communication & understanding	**24.94**	**23.70**	**21.96**
Impact on personal future	10.05	11.04	10.48
Friends' reactions	13.22	12.94	12.60
Parent / child relationship	10.65	10.43	9.53
Global well-being	**9.94**	**9.12**	**8.53**
PIIS total score	158.80	154.59	148.08

Table 7.6: Mean PIIS-R subscale and total scores by illness group

Percentage scores and comparisons between illness groups for PIIS-R dichotomous items 43-56 are presented in table 7.7. Three items reach statistical significance. For item 49, significantly fewer children of stroke patients report their parents talking to them about their condition than do children of parents with PD or PWMS (x^2 = 11.19, p <0.01). For item 53, significantly more children of stroke patients than children of parents with PD or PWMS would welcome the opportunity for counselling as a family (x^2 = 8.97, p <0.01). For item 54, significantly fewer children of stroke patients than children of parents with PD or PWMS report the availability of external help to care for their affected parent (x^2 = 6.30, p <0.05).

	PD		MS		Stroke				
PIIS Item	**% Yes**	**% No**	**% Yes**	**% No**	**% Yes**	**% No**	x^2	**df**	p
43 – Have enough information	62.5	37.5	57.1	42.9	53.8	46.2	0.775	2	.679
44 – Know enough about what will happen in the future to unwell parent	46.3	53.8	43.5	56.5	42.3	57.7	0.170	2	.919
45 – Rely solely on parents for information about parent's illness	61.3	38.8	68.3	31.7	76.0	24.0	2.051	2	.359
46 – Have somebody to talk to about parent's illness if want to	70.4	29.6	69.8	30.2	65.4	32.1	0.238	2	.888
47 – Have support from friends and family	81.3	18.7	77.0	23.0	80.8	19.2	0.398	2	.819
48 – Have ways to cope with any feelings of anger	74.5	25.5	72.5	27.5	57.1	42.9	2.245	2	.326
49 – Parent talks about their illness	77.5	22.5	66.7	33.3	42.3	57.1	11.19	2	**.004****
50 – Would help to have contact with people in similar circumstances	43.6	56.4	29.0	71.0	46.2	53.8	3.818	2	.148
51 – Would help to have training in giving practical care	52.5	47.5	37.1	62.9	52.0	48.0	3.638	2	.162
52 – Would be helpful to have opportunity for counselling	35.0	65.0	31.7	68.3	48.0	52.0	2.081	2	.353
53 – Would help to have counselling as family	21.5	78.5	22.2	77.8	50.0	50.0	8.976	2	**.011****
54 – Outside help available to help care for affected parent	40.8	59.2	55.0	45.0	26.9	73.1	6.306	2	**.043***
55 – Think more help (e.g. meals on wheels, physiotherapy) should be provided by services	61.0	39.0	61.9	38.1	62.5	37.5	0.021	2	.990
56 – Would help to be able to talk to local services about help provided to parent	40.5	59.5	28.6	71.4	50.0	50.0	4.028	2	.133

** p < 0.01
* p < 0.05

Table 7.7: Analysis of PIIS-R items 43-56 by illness group

(7-3-iii) Parental illness group comparisons of child psychosocial well-being: Tables 7.8, 7.9, and 7.10 report comparisons of psychosocial factors between children of parents with PD, PWMS and stroke patients. ANOVA results show differences between groups in quality of social support for participants aged 11-17 (f=4.191, p<0.05), quality of attachment for those aged 11-17 (f=5.336, p<0.00), and positive family coping (f=4.130, p<0.05). Tukey pairwise comparisons reveal statistically significant differences between children of parents with Parkinson's and PWMS in positive attachment (p<0.01), and positive family coping (p<0.05). Comparisons also show significant differences between children of parents with Parkinson's and stroke patients in adolescent social support (p<0.05).

	df	*f*	*p*
Parentification Questionnaire – Youth	2, 48	1.762	.183
Rosenberg Self-Esteem Questionnaire	2, 164	2.238	.110
Social Support Scale for Children	2, 38	4.191	**.023**
Inventory of Parent & Peer Attachment	2, 48	5.336	**.008**
Family Coping Scale	2, 161	4.130	**.018**
EUROQOL Visual Analogue Scale	2, 112	1.685	.190
Parentification Questionnaire - Adult	2, 113	2.159	.120
Social Support Questionnaire	2, 108	1.772	.175
Family Environment Scale	2, 66	1.728	**.186**

Table 7.8: Psychosocial comparisons between children of parents with Parkinson's, PWMS, and stroke patients

Table 7.9 presents Kruskal-Wallis non-parametric comparisons between groups. No significant differences are reported, although Beck depression scores for adult children just fail to meet significance (x^2=5.588, p>0.05).

	df	x^2	*p*
Birleson Depression Inventory	2, 48	2.180	.336
Beck Depression Inventory	2, 111	5.588	.061

Table 7.9: Non-parametric comparisons between children of parents with Parkinson's, PWMS, and stroke patients from the DSRS & BDI

Table 7.10 presents mean scores by disease group for significantly different psychosocial factors. The same trend is evident as in QoL scores, with children of stroke patients report the lowest scores, followed by children of PWMS, and children of parents with PD reporting the highest. The single exception to this is the inferior attachment reported by children of PWMS, who score slightly lower than children of stroke victims. Beck depression scores for adult children, whilst not significant, are shown for illustrative purposes.

	PD	MS	Stroke
Social Support Scale for Children	84.38	77.07	72.81
Inventory of Parent & Peer Attachment	119.31	99.54	104.81
Family Coping Scale	90.62	85.22	83.84
Beck Depression Inventory	6.20	7.27	9.64

Table 7.10: Mean scores between disease groups for the SSSC, IPPA, FCS, & BDI

(7-3-iv) Predictive factors: Regression analysis showed no significant predictors of QoL for either adolescent or adult children of PWMS or stroke patients. The significant predictor for adult children of parent's with PD, mental health, was reported in chapter 6.

(7-3-v) Levels of self-reported depression: To further explore mental well-being, tables 7.11, 7.12 and 7.13 show the percentage of participants reporting depression. Table 7.11 shows percentages for both adolescent and adult children by disease group. Table 7.12 breaks this down further by reporting percentages for adolescent and adult children by disease group. Table 7.13 shows percentages of self-reported depression for adult children by the wildly accepted BDI classifications of mild, moderate, and severe depression.

	% reporting depression
PD	17.7%
MS	31.1%
Stroke	36.0%

Table 7.11: Percentage of children depressed by disease group

	% reporting depression aged 11-17	% reporting depression aged 18 and above
PD	12.5%	17.7%
MS	20.8%	37.8%
Stroke	18.2%	50.0%

Table 7.12: Percentage of adolescent and adult children reporting depression by disease group

	Mild	Moderate	Severe	Total
PD	14.3%	3.2%	3.2%	17.7%
MS	37.8%	0.0%	0.0%	37.8%
Stroke	28.6%	21.4%	0.0%	50.0%

Table 7.13: Percentage of adult children reporting mild, moderate, and severe depression by disease group.

(7-3-vi) Parental illness group comparisons of child QoL by sociodemographic variables: Comparisons of QoL by sociodemographic variables for children of parents with Parkinson's were reported in chapter 6. The following section reports comparisons of QoL for children of PWMS and stroke patients.

(7-3-vi-a) ***Comparisons of QoL by sociodemographic variables for children of PWMS*****:** Table 7.14 displays comparisons of PIIS-R subscale and total scores between those children who remain in the parental home and those that do not. Children who remain in the parental report a significantly heightened burden of daily help than children who have left home (t=-3.64, p<0.01). Similarly, with regard to friends' reactions, children who still live at home report significantly greater difficulty than those that have left the family home (t=-3.86, p<0.00). Conversely, and only moderately significantly, children of PWMS that have left the family home report inferior global well-being (t=.048, p<0.05), whilst impact on personal future just fails to meet significance (t=1.976, p>0.05).

	Mean			
	At parental Home	Not at parental Home	*t*	*P*
Burden of daily help	28.09	33.76	-3.641	**.001**
Emotional impact	14.38	14.67	-.325	.747
Social impact	24.34	26.15	-1.536	.130
Communication & understanding	23.96	23.44	.342	.733
Impact on personal future	11.80	10.28	1.976	**.053**
Friends' reactions	11.81	14.07	-3.860	**.000**
Parent / child relationship	10.45	10.41	.051	.960
Global well-being	9.70	8.54	2.024	**.048**
PIIS total score	**150.93**	**158.26**	**-1.271**	**.209**

Table 7.14: Comparison of mean PIIS-R subscale and total scores for children of PWMS living within the parental home and those not in the parental home

Table 7.15 displays non-parametric comparisons between PIIS-R scores for children of PWMS between only children and those with siblings. Only children report significant greater difficulties with communication and understanding (z=-2.061, p<0.05), friends' reactions (z=-2.664, p<0.01), and lower total QoL scores (z=-2.169, p=<0.05).

	Mean			
	Only Child	Siblings	*z*	*P*
Burden of daily help	30.28	31.01	-.635	.525
Emotional impact	12.57	14.78	-1.463	.143
Social impact	23.42	25.48	-1.694	.090
Communication & understanding	18.98	24.30	-2.061	**.039**
Impact on personal future	9.84	11.20	-1.291	.197
Friends' reactions	10.57	13.24	-2.664	**.008**
Parent / child relationship	9.28	10.58	-1.178	.239
Global well-being	8.14	9.25	-.981	.327
PIIS total score	**139.11**	**156.56**	**-2.169**	**.030**

Table 7.15: Comparison of mean PIIS-R subscale and total scores for children of PWMS with and without siblings

No significant differences observed by gender of child or gender of affected parent for children of PWMS

(7-3-vi-b) Comparisons of QoL by sociodemographic variables for children of stroke patients: Table 7.16 displays comparisons of PIIS-R subscale and total scores between those children who remain in the parental home and those that do not for children of stroke patients. The sole significant difference observed is children who remain in the parental reporting a greater degree of social impact than those who have left (z=-2.119, p<0.05). It should be noted, that whilst not significant, this trend is seen across virtually almost all domains.

	Mean			
	At parental Home	Not at parental Home	*z*	*P*
Burden of daily help	27.73	31.30	-1.664	.096
Emotional impact	14.13	16.00	-1.413	.158
Social impact	23.53	26.65	-2.119	**.034**
Communication & understanding	22.00	21.92	-.052	.958
Impact on personal future	9.93	11.24	-1.280	.200
Friends' reactions	12.13	13.24	-1.144	.253
Parent / child relationship	9.33	9.81	-.132	.895
Global well-being	9.20	7.63	-1.259	.208
PIIS total score	**144.06**	**153.55**	**-1.428**	**.153**

Table 7.16: Comparison of mean PIIS-R subscale and total scores for children of stroke patients living within the parental home and those not in the parental home

Table 7.17 displays comparisons by gender of child for children of stroke patients. The sole significant result shows males reporting greater difficulties with friends' reactions than females (z=-2.394, p<0.05).

	Mean			
	Male	Female	*z*	*P*
Burden of daily help	28.20	30.66	-1.092	.275
Emotional impact	14.80	15.09	-.052	.958
Social impact	24.00	26.02	-1.360	.174
Communication & understanding	22.33	21.46	-.886	.375
Impact on personal future	10.13	10.97	-.418	.676
Friends' reactions	11.66	13.87	-2.394	**.017**
Parent / child relationship	9.73	9.27	-.631	.528
Global well-being	8.46	8.63	-.524	.600
PIIS total score	**145.06**	**152.19**	**-.649**	**.516**

Table 7.17: Comparison of mean PIIS-R subscale and total scores for children of stroke patients by gender of child

Table 7.18 displays PIIS-R comparisons by gender of parent for children of stroke patients. Children of fathers who have suffered a stroke report greater difficulties with communication and understanding (z=-2.568, p<0.01) and friends' reactions (z=-2.620, p<0.01) than children of mothers who have suffered a stroke. Whilst other domains and total scores do not reach statistical significance, the same trend is evident.

	Mean			
	Mother affected	Father affected	*z*	*P*
Burden of daily help	29.63	29.00	-.211	.833
Emotional impact	15.10	14.81	-.372	.710
Social impact	26.32	23.93	-1.833	.067
Communication & understanding	24.81	20.18	-2.568	**.010**
Impact on personal future	11.27	10.00	-.955	.339
Friends' reactions	14.02	11.71	-2.620	**.009**
Parent / child relationship	10.60	8.57	-1.336	.182
Global well-being	8.60	8.50	-.346	.729
PIIS total score	**156.77**	**142.64**	**-1.713**	**.087**

Table 7.18: Comparison of mean PIIS-R subscale and total scores for children of parents with stroke by gender of affected parent

Comparisons between only children and those with siblings were not possible due to sample size.

(7-3-vii) Socio-demographic and QoL correlations: The following section reports Sociodemographic and QoL correlations for children of PWMS and stroke patients.

(7-3-vii-a) ***Socio-demographic and QoL correlations for children of PWMS:*** Table 7.19 displays correlations between children of PWMS PIIS-R scores and socio-demographic variables. Childs current age correlates positively with PIIS-R subscale friends' reactions (r=.485, p<0.01) and burden of daily help (r=.369, p<0.01). Child age at diagnosis correlates negatively but weakly with PIIS-R subscales parent / child relationship (r=-.293, p<0.05) and global well-being (r=-.277, p<0.05).

	Child's age	Childs age at diagnosis
Burden of daily help	**.369****	.128
Emotional impact	.097	-.083
Social impact	.230	.099
Communication & understanding	-.067	-.228
Impact on personal future	-.110	.038
Friends' reactions	**.485****	.107
Parent / child relationship	-.151	**-.293***
Global well-being	-.193	**-.277***
PIIS total score	**.170**	**-.064**

** Correlation significant at 0.01
* Correlation significant at 0.05

Table 7.19: Correlations between PIIS subscales and total score and child's current age, and age at diagnosis of parent's condition for children of PWMS

Table 7.20 displays correlations between children of PWMS PIIS-R scores and further socio-demographic variables. Distance from parents home correlates positively with PIIS-R total score (r=.339, p<0.01), and subscales burden of daily help (r=.434, p<0.01), social impact (r=.342, p<0.01), and friends' reactions (r=.484, p<0.01). Number of siblings correlates positively but weakly with PIIS-R total score (r=.278, p<0.05), and PIIS subscales social impact (r=.293, p<0.05) and highly significantly with communication and understanding (r=.344, p<0.01).

	Socioeconomic classification	Distance from parents home	Number of siblings
Burden of daily help	-.119	**.434****	.106
Emotional impact	-.187	.226	.241
Social impact	-.090	**.342****	**.293***
Communication & understanding	-.194	.192	**.344****
Impact on personal future	-.313	-.068	.239
Friends' reactions	-.289	**.484****	.173
Parent / child relationship	-.038	.064	.003
Global well-being	-.275	-.124	.016
PIIS total score	**-.252**	**.339****	**.278***

Table 7.20: Correlations between PIIS-R subscales and total score, and socioeconomic classification, proximity to the parental home and number of siblings for children of PWMS

(7-3-vii-b) ***Socio-demographic and QoL correlations for children of stroke patients:*** Table 7.21 displays correlations between children of stroke patients PIIS-R scores and socio-demographic variables. Childs current age correlates positively with PIIS-R subscale friends' reactions (r_s =.554, p<0.01) and negatively but weakly with global well-being (r_s =-.443, p<0.05). Child age at diagnosis correlates positively but weakly with PIIS-R subscales friends reactions (r_s =.450, p<0.05).

	Child's age	Childs age at diagnosis
Burden of daily help	-.096	-.062
Emotional impact	-.096	-.215
Social impact	.151	.162
Communication & understanding	.035	.014
Impact on personal future	-.004	-.031
Friends' reactions	**.554****	**.450***
Parent / child relationship	.106	.065
Global well-being	**-.443***	-.330
PIIS total score	**.018**	**-.001**

** Correlation significant at 0.01
* Correlation significant at 0.05

Table 7.21: Correlations between PIIS-R subscales and total score and child's current age, and age at diagnosis of parent's condition for children of stroke patients

Table 7.22 displays correlations between children of stroke patients PIIS-R scores and further socio-demographic variables. Socioeconomic classification correlates positively with PIIS-R total score (r_s =.554, p<0.05), and subscales social impact (r_s =.698, p<0.01), communication and understanding (r_s =.486, p<0.05) and friends' reactions (r_s =.696, p<0.01). Number of siblings correlates positively with PIIS-R subscales social impact (r_s =.446, p<0.05) impact on personal future (r_s =.419, p<0.05) and friends' reactions (r_s =.423, p<0.05).

	Socioeconomic classification	Distance from parents home	Number of siblings
Burden of daily help	.176	.261	.225
Emotional impact	.094	.347	.126
Social impact	**.698****	.393	**.446***
Communication & understanding	**.486***	.081	-.121
Impact on personal future	.332	.273	**.419***
Friends' reactions	**.696****	.115	**.423***
Parent / child relationship	-.100	.140	-.170
Global well-being	.414	-.202	-.157
PIIS total score	**.554***	**.275**	**.247**

Table 7.22: Correlations between PIIS-R subscales and total score, and socioeconomic classification, proximity to the parental home and number of siblings for children of stroke patients

(7-3-viii`) Further analysis by siblings: To gain a more powerful insight into the impact of sibling support an analysis of data from 'only children' across all three groups was compared with those with siblings. Tables 7.23 and 7.24 report comparisons of QoL by number of siblings. Results of ANOVA presented in table 22 show significant differences in four subscales and total PIIS-R scores. Subscales emotional impact (f=2.99, p<0.05), social impact (f=3.59, p<0.05) communication and understanding (f=4.37, p<0.01) and impact on personal future (f=3.05, p< 0.05) all meet statistical significance, as does PIIS-R total (f=3.42, p<0.05). Calculating Tukey pairwise comparisons to adjust for multiple comparisons reveals statistically significant differences between children with no siblings and those with two siblings in emotional impact (p<0.05), and children with no siblings and those with 2 siblings (p<0.05) and 3 or more siblings (p<0.05) in communication and understanding.

	df	*f*	*p*
Burden of daily help	3, 165	1.901	.131
Emotional impact	3, 165	2.997	.032
Social impact	3, 165	3.597	.015
Communication & understanding	3, 165	4.378	.005
Impact on personal future	3, 165	3.052	.030
Friends' reactions	3, 165	2.132	.098
Parent / child relationship	3, 165	0.491	.689
Global well-being	3, 165	2.374	.072
PIIS total score	3, 165	3.424	.019

Table 7.23: Analysis of variance of PIIS-R by number of siblings

Although significant pairwise comparisons are limited to the three reported above, table 23 shows an almost unbroken uniformity of mean scores, whereby only children report inferior QoL to those with siblings.

	Only child	1 sibling	2 siblings	3+ siblings
Burden of daily help	32.01	29.89	32.53	31.05
Emotional impact	13.06	14.64	15.56	15.55
Social impact	23.81	24.93	26.68	26.87
Communication & understanding	20.80	23.20	25.28	25.74
Impact on personal future	9.49	9.94	11.18	11.14
Friends' reactions	12.25	12.66	13.51	13.49
Parent / child relationship	10.12	10.67	10.15	10.33
Global well-being	8.58	9.35	10.09	8.81
PIIS total score	**146.322**	**151.78**	**161.54**	**159.80**

Table 7.24: Mean PIIS-R Subscale and total scores by number of siblings

To further explore these results 'only children' from all three groups are compared with those with siblings, as seen in table 7.25. Significant differences are reported between only children and those with siblings in PIIS-R subscales social impact (z=-2.234, p<0.05), and communication and understanding (z=-2.224, p<0.05), and PIIS total scores (z=-2.033, p<0.05).

	Mean			
	Only child	Siblings	*z*	*p*
Burden of daily help	32.01	30.98	-0.333	.739
Emotional impact	13.06	15.12	-1.816	.069
Social impact	23.81	25.88	-2.343	**.019**
Communication & understanding	20.80	24.36	-2.224	**.026**
Impact on personal future	9.49	10.58	-1.320	.187
Friends' reactions	12.25	13.10	-1.271	.204
Parent / child relationship	10.12	10.43	-0.544	.586
Global well-being	8.58	9.51	-1.464	.143
PIIS total score	**146.322**	**156.58**	-2.033	**.042**

Table 7.25: Comparison of mean PIIS-R subscale and total scores for children with and without siblings

(7-3-ix) Relationships with parent well-being: The following section reports correlations with parent well-being for children of PWMS and stroke patients.

(7-3-ix-a) Correlations with parent's ADL, QoL, mental health and disease duration for children of PWMS: Table 7.26 displays Pearson correlation coefficients between children of PWMS PIIS-R scores and parent variables. Significant positive correlations are observed between the parent with MS QoL score and PIIS-R total score (r=.391, p<0.01) and the subscales emotional impact (r=.509, p<0.05) social impact (r=.342, p<0.05), and communication and understanding (r=.362, p<0.05). Parental level of depression correlates negatively with PIIS-R total score (r=-.489, p<0.01) and PIIS-R subscales emotional impact (r=-.548, p<0.01), social impact (r=-.321, p<.05), communication and understanding (r=-.514, p<0.01), impact on personal future (r=-.316, p<0.05), parent / child relationship (r=-.398, p<0.01), and global well-being (r=-.347, p<0.05). Parental disease duration correlates positively with PIIS-R subscale friends' reactions (r=.405, p<0.01), burden of daily help (r=.264, p<0.05), and PIIS-R total score (r=.259, p<0.05).

	Parent's ADL score	Parent's QoL score	Parent's level of depression	Parents disease duration
Burden of daily help	-.031	.221	-.189	.264*
Emotional impact	.095	.509**	-.548**	.214
Social impact	.022	.342*	-.321*	.142
Communication & understanding	.209	.362*	-.514**	.177
Impact on personal future	.178	.192	-.316*	-.152
Friends' reactions	-.277	.109	-.022	.405**
Parent / child relationship	.237	.099	-.398**	.144
Global well-being	.252	.127	-.347*	.100
PIIS total score	**.134**	**.391****	**-.489****	**.259***

** Correlation significant at 0.01
* Correlation significant at 0.05

Table 7.26: Correlations between PIIS-R subscales and total score, the affected parent's ADL score, QoL and level of depression, and the unaffected parent's QoL score for children of PWMS

(7-3-ix-b) Correlations with unaffected parent's QoL for children of PWMS: The unaffected parents QoL score correlates positively with PIIS-R subscales communication and understanding (r=.487, p<0.01), and parent / child relationship (r.458, p<0.01).

(7-3-ix-c) Correlations with parent's ADL, QoL, mental health and disease duration for children of stroke patients: Table 7.27 displays Spearman correlation coefficients between children of stroke patients PIIS-R scores and parent variables. Parents ADL score correlates negatively with PIIS-R subscale parent / child relationship (r_s=-.548, p<0.05), and positively with global well-being (r_s=.579, p<0.05). Parental QoL correlates negatively with PIIS-R subscale communication and understanding (r_s -.650, p<0.05). Parental disease duration correlates positively with PIIS-R subscale emotional impact (r_s =.537, p<0.01).

	Parent's ADL score	Parent's QoL score	Parent's level of depression	Parents disease duration
Burden of daily help	.222	.200	.167	.166
Emotional impact	-.408	-.280	.362	**.537****
Social impact	.000	-.207	.361	.258
Communication & understanding	-.243	**-.650***	.384	.009
Impact on personal future	-.204	-.163	.283	.224
Friends' reactions	.031	-.055	.218	.090
Parent / child relationship	**-.548***	-.454	.047	.006
Global well-being	**.579***	.345	.318	.162
PIIS total score	**-.107**	**-.291**	**.360**	**.282**

** Correlation significant at 0.01
* Correlation significant at 0.05

Table 7.27: Correlations between PIIS-R subscales and total score, the affected parent's ADL score, QoL and level of depression, and the unaffected parent's QoL score for children of stroke patients

(7-3-ix-d) Correlations with unaffected parent's QoL for children of stroke patients: No significant correlations were established between the QoL of the unaffected parent and the QoL of the child.

(7-4) Discussion

The hypotheses outlined at the beginning of this chapter are partially confirmed by data from the three groups assessed. The hypothesis that there would be significant differences in QoL between children of parents with PD, MS and stroke QoL was confirmed in two components of QoL as measured by the PIIS-R with a consistent trend seen in other dimensions. The hypothesis that there would be significant differences in psychosocial well-being between children in the three groups was also partially accepted with significant differences seen in a number of variables assessed. The final two hypotheses that there would be differences in the sociodemographic variables, and in the relationship between child QoL and parental well-being, implicated in children's response to each parental condition was largely supported. These results will now be discussed in further detail

Analysis of data from the PIIS-R shows a fairly consistent trend with the impact of the parental condition being strongest in children of stroke patients, followed then by children of PWMS, with children of parents with PD showing the least impact in many of the domains measured. Statistically significant differences are seen in the domains of communication and understanding and global well-being, with children of stroke patients reporting significantly lower scores. Although not statistically significant, there are two noticeable exceptions to the pattern of results seen in the three parental illness groups. Children of parents with Parkinson's report greater concern for their future than do both children of PWMS and stroke patients. One possible explanation for this might be the protracted, uncertain, less visible deterioration over many years evident in PD, causing children to think more 'long-term' about the potential impact to them of their parent's condition. With MS being a condition of much earlier onset and more visible deterioration it is possible that children of PWMS adjust their sights more realistically with a degree of acceptance with regard to the future. Further research is required to test this hypothesis. The other result worthy of note from analysis of the PIIS-R is the emotional impact of parental illness appears most profound in children of PWMS, a finding discussed further later

The results from the dichotomous items of the PIIS-R are similar across the three groups in all but three areas. In all three groups approximately 60% report having enough information currently about their parents condition, with approximately 40% reporting knowing enough about what will happen to their affected parent in the future. Again the message here is clear; many children feel they have enough

information at the present moment but possibly not for the future. As discussed in chapter 6, children of all ages should be allowed access to information at a time that is comfortable and appropriate for them, and the key remains to have this available when required. The only significant differences are reported by children of stroke patients, and their interpretation is relatively straightforward. Significantly fewer children from this group report their parent talking to them about their condition, most likely reflecting the cognitive impairment of the parent. Notably, 50% of children of stroke patients feel counselling as a family unit would be helpful, highlighting the significant strain stroke places on the family as reported in other studies (i.e. Smout, 2001). Of most concern, however, is the fact that 73% of children of stroke patients report no external assistance in helping care for their parent whilst 55% of children of PWMS, and 41% of children of parents with Parkinson's report the availability of outside help. On the one hand the lower levels of assistance for stroke families may be due to a high degree of recovery; all were 2-7 years post stroke. Measurement of the degree of cognitive impairment was beyond the scope of this study. Alternatively this result may reflect poor service provision on the part of stroke services, and the fact that 62.5% of children of stroke patients think more external assistance should be provided would seem to support this.

The trend by disease group seen in analysis of QoL as measured by the PIIS-R is further supported by analysis of psychosocial variables. Significant differences are seen between children of stroke patients and those of parents with Parkinson's in social support, positive family coping strategies, and levels of depression. In all of these domains children of PWMS also score lower than children of parents with Parkinson's, but all fail to reach statistical significance. The exception to this trend is the significantly less positive attachment reported by children of PWMS compared to those of parents with Parkinson's. It should be noted that children of stroke patients also report considerably less positive attachment. Initially this may seem difficult to interpret as attachment is regarded as a relatively stable emotional bond to a parent or significant other, first established in infancy (Bowlby, 1969), and as such significant differences would not be expected. Research has shown, however, that parents continue to influence the well-being of children during adolescence (Ainsworth, 1989). Importantly for the finding reported here, and as Arbona & Power (2003) point out, it is argued that it is confidence in the availability of the parent that is key to the adolescent's psychological well-being. The nature of a young-onset chronic progressive illness such as MS, and acute incident such as stroke may indeed lead to reduced availability of the attachment figure as a result of motor,

cognitive and emotional changes. The implications of this are clear from the research literature; securely attached adolescents have been shown to report superior life-satisfaction, heightened self-esteem, greater levels of perceived social support and less psychological distress (Armsden & Greenberg, 1987; Blain *et al.*, 1993).

Levels of self-reported depression in both adolescent and adult children in all three groups are of significant concern. Prevalence of depression in adults in the general population is estimated at 5%-10% (Singleton *et al.*, 2001), and in adolescents at anywhere between 2-6% (Hazell, 2002) and 5%-8% (Son & Kirchner, 2001). The only data that appears to exist on reported levels of depression related to parental illness is that provided by Schrag *et al.* (2004) where approximately 20% of children of parents with Parkinson's were found to be at least mildly depressed. The figure for the children of parents with Parkinson's from the current sample stands at 17.7%. As the group reporting the least amount of depressive symptoms, and breaking this down into adolescent and adult children, both groups report over twice that of the normal population. The figures for children of PWMS and stroke patients, however, are striking, with 31.1% of children of PWMS and 36% of children of stroke patients reporting at least mild depression. Breaking these down again into adolescent and adult participants we see adolescents from both groups reporting over three times that seen in the normal population. With just under 40% of adult children of PWMS reporting mild depression and a half of the adult children of stroke patients reporting mild-moderate depression the mental health of children of unwell parents is a clear issue for general practitioners and service providers alike.

Adolescence has consistently been shown to be a period of heightened risk for the onset of depressive symptoms (Sheffield *et al.*, 2004). Despite this, depression often goes unrecognised in both adolescents (Kramer & Garralda, 2000) and adults (Freeling *et al.,* 1985) in primary care. Research has shown that this is particularly so in those with milder bouts of depression (e.g. Ronalds *et al.*, 1997; Simon *et al.*, 1999), as reported by the majority of participants in this study. As a result some have called for routine screening via administration of standardised depression inventories (Wright, 1994). Some though have concluded that such practice is not cost-effective, fails to improve detection, and that further research is required if this is to improve (Gilbody *et al.*, 2001). The importance of detection though is clear. As stated in chapter 1, unrecognised depression in adolescence can lead to poor educational attainment and psychosocial outcomes, as well as continuing into adulthood (Birmaher *et al.*, 1996). Poor detection in adulthood can lead to poor treatment

outcomes as well as the economic cost through lost working days and increased use of the medical system (Wells *et al.*, 1992).

Analyses of a number of sociodemographic variables were undertaken. An assessment was made of each family's socioeconomic-status (SES), as the changing of family roles, so evident with serious medical conditions, can lead to altered financial status (Ekberg *et al.*, 1986). With particular reference to PD, Whetton Goldstein *et al.* (1997) point out that the direct cost of the illness is minor when compared to the more covert costs of loss of wages, changing roles and informal care. As the disease progresses in the patient, so the QoL and financial status of the family worsens. The financial implications of MS and stroke are also well recognised (i.e. Hewer, 1997). This change in SES has the potential to have major implications for children and adolescents. Children and adolescents from low SES backgrounds have been shown to have inferior health than their counterparts from high SES backgrounds, show lower academic attainment, and inferior socioemotional development (Bradley & Corwyn, 2002). Research has also shown that the impact of low SES becomes greater with increasing negative life events and risk factors such as loss of employment and parental mental illness (Brooks-Gunn *et al.*, 1995; Sameroff *et al.*, 1993).

No correlations between SES and children of PWMS PIIS scores were observed, and only one factor correlated with SES in children of parents with Parkinson's, that of friends' reactions. Correlations between SES and the QoL of children of stroke patients however are striking, particularly in light of the very small sample. Such results serve to highlight the financial implications of an acute episode such as stroke, and their impact not just on the individual, but on the family unit as a whole. However, the correlations between QoL and socioeconomic status based on this sample should be viewed with a high degree of caution as the sample was highly skewed with 67% of families standing within the top bracket of classification. However, with such a high proportion of families from this sample described as 'professional' (Office for National Statistics) it is highly likely that those in a less financially sound position find the onset and progression of serious illness to be of much greater impact. Additionally, as previously stated, there is the likelihood of worsening financial status as the illness progresses (Whetton Goldstein *et al.*, 1997).

Correlations between QoL and number of siblings, and results showing significant differences between only children and those with siblings appear intuitive, but the

literature on sibling relationships is sparse, with even less focusing on sibling support, and none focusing specifically on sibling support in parental chronic illness. It would appear wholly reasonable to speculate that the reasons for only children scoring lower QoL is their inability to access support from a sibling. This fits well with the so-called 'compensatory siblings hypothesis' (Boer *et al.*, 1992). Here siblings use each other as a resource to make up for deficiencies in the parent-child relationship. This theory is controversial however, and contradicted by the 'congruence hypothesis' (Sanders, 2004). Consistent with social learning theory the 'congruence hypothesis' contends that positive interactions between children and their parents fosters positive interactions between the siblings themselves. In short, there appears evidence for both theories (Bryant & Crockenberg, 1980; Dunn & Kendrick, 1982; Hetherington, 1988), and factors such as developmental stage and individual differences may play an important role in which hypothesis is of most value (Dunn, 1988). This result requires further investigation. For example, it would be beneficial to investigate whether only children form closer bonds with peers at, for example, school, or other significant others such as extended family members.

Disease group specific comparisons of sociodemographic variables follow a similar pattern across the three groups. Whilst not all results reach statistical significance, those that remain in the parental home report inferior QoL and greater impact from their parent's condition. This again highlights the reality of living with parental illness on a daily basis, and the need for services to recognise the needs of, and provide support for these children. That significant correlations were established between children's QoL scores and proximity to their unwell parent, serves to reinforce the greater impact of living with or close to the affected parent. A specific area where sociodemographic influences on QoL did differ, however, was that of gender. As reported in the previous chapter, female children of parent's with Parkinson's reported considerably lower scores than their male counterparts. For children of PWMS differences between male and female children were negligible, and no significant differences were observed. For children of stroke patients we see a complete reversal in comparison to children of parents with Parkinson's with males reporting inferior QoL as compared to females. This would appear to contradict the findings that females are more reliant (Moore, 1987) and dependent (Frank *et al.*, 1990; Paterson *et al.*, 1994) on their parents than males. A high degree of caution is necessary with this finding due to the small sample size of children of stroke patients. A clue as to why this might be may lie in the gender of the affected parent. Only with children of stroke patients was the gender of the parent remotely significant, those

with an affected father reporting greater impact. It may well be that the sudden onset of stroke plunges male children into taking on a 'man of the house' role. Analysis of the interaction between these factors was not possible due to sample size, but is clearly worthy of further investigation.

As mentioned earlier the emotional impact of parental MS appears particularly profound, and is further highlighted in correlations with parent reports of mental well-being and QoL. In stark contrast to children of PD and stroke patients, highly significant correlations are observed between the PWMS level of depression and the QoL of the child in almost all dimensions as measured by the PIIS-R. This is not seen in children of Parkinson's patients where the only significant correlations with the affected parent are with their ability to perform activities of daily living. No significant correlations were observed with the PWMS ADL scores and the child's QoL. This suggests it is the emotional manifestations of MS that have the clearest implications for the child, whereas it is the practical impact of PD that has the greatest affect on children of parents with PD. It is difficult to draw firm conclusions regarding children of stroke patients, due to the small sample size. What does seem reasonable to suggest from the non-parametric data is that the practical impact of parental stroke has a significant affect on these children. Whilst no correlations were evident between children of stroke patients QoL and their parent's mental health, the mental health of the children themselves cannot go unrecognised as discussed previously.

Correlations between parental disease duration and children's QoL shed light on previously discussed results. Few domains are statistically significant for each of the three groups but a consistent pattern does emerge. For children of parent's with Parkinson's the negative impact of their parent's condition appears to increase as the disease progresses. Again this may reflect the impact of the slow deterioration over a number of years that is characteristic of Parkinson's. For children of PWMS and stroke patients the opposite is the case. This is perhaps unsurprising in the case of children of stroke patients where a degree of recovery may occur. The result is counterintuitive for children of PWMS, but as stated in the beginning of this chapter that MS is a condition of much earlier onset and more visible deterioration it is possible that children are more realistic and adapt accordingly to their parent's condition.

No correlations were observed with the unaffected parent's QoL for children of parent's with Parkinson's and stroke patients. For children of PWMS, however, highly

significant correlations were seen with PIIS-R subscales communication and understanding and parent / child relationship. This implies that the well-being of the unaffected parent may be equally important to the well-being of the child. As stated in chapter 6, it may be of benefit to investigate further variables from the non-affected parent such as mental health.

(7-5) Chapter summary

This chapter has highlighted significant differences and trends seen across the three parental illness groups. Issues surrounding the emotional well-being of children when confronted with parental illness, the importance of social support as highlighted by the inferior QoL of children without the support of siblings, and the possible harmful effects of low SES have also been discussed. In the following concluding chapter an attempt is made to discuss how these results can be of practical benefit, how best this research can be developed further, and limitations of the current study.

Chapter 8: Conclusions & Implications for Future Research

(8-1) Introduction: Data from the studies presented provide us with valuable insights into the challenges faced by adolescent and adult children of parents with chronic or acute neurological illness. Although not all hypotheses were confirmed, results demonstrate the potentially negative impact of parental illness on these children, and this will be of interest to policy makers, service providers, the medical profession and support charities.

(8-1-i) Aims of chapter: The aim of this final chapter is to draw together the key findings discussed in previous chapters, and demonstrate how these might be of practical benefit. Specifically the chapter aims to:

- Address government policy through discussion of current national guidelines and highlight their limitations.
- Indicate how results presented might have implications for service providers.
- Discuss potential areas for future research
- Highlight the limitations of research presented in this thesis.

(8-2) National Guidelines: As stated, results from the three conditions investigated show the potentially negative impact, to varying degrees, on children's QoL and psychosocial well-being. In assessing published clinical guidelines for each condition there is a wide disparity in recognition of this. There follows a brief review of each guideline, with emphasis on the extent to which each addresses the findings presented in this thesis. This is followed by discussion of the government's National Service Framework, and further guidelines relevant to this thesis relating to mental health.

(8-2-i) National Clinical Guideline for Parkinson's Disease: The first National Institute for Health & Clinical Excellence (NICE) guidelines for Parkinson's disease were published in July 2006 (National Institute for Health & Clinical Excellence, 2006), with an expected review date of 2010. The document makes no reference to the children of people with Parkinson's. Early in these guidelines there is a focus on 'communication with people with Parkinson's disease and their carers'. The section is introduced by highlighting that 'good communication is at the heart of every interaction between people with PD their carers and health professionals'. Results

reported in this thesis underline that this communication must also extend to the children of those with PD, be they young or adult. Nearly 40% of participants reported not having enough information about their parent's PD, and over 50% reported similarly in the study of Schrag *et al.* (2004a).

The section of the guidelines focusing on palliative care makes a number of references to the carers and families of patients, but none specifically directed towards their children. The overriding theme of this section is based on the WHO guidelines of achieving 'the best quality of life for patients and their families' (World Health Organisation, 2002). The section discusses issues surrounding, for example, care homes, withdrawal of drugs, pressure ulcers, and ethical issues, and has a subsection entitled 'palliative care and carers'. Here it is suggested that a 'care pathway' be incorporated for carers in assisting them to adjust to the palliative phase of the disease, and refers to the information made available by the PDS in the form of information sheets. Again it seems appropriate on the evidence provided in this thesis that all such recommendations should consider patient's children, and not focus exclusively on their carers.

(8-2-ii) National Clinical Guideline for Stroke: The National Clinical Guidelines for Stroke produced by the Royal College of Physicians (2004) again make little reference to the potential needs of children of stroke patients. The guidelines do recognise that stroke is a 'family illness' and focus on the needs of carers in relation to ongoing support and information from the acute phase through to any longer term needs. The document also acknowledges the needs of younger stroke patients in relation to their raising a family. Provision of information for patients and family members is highlighted as an area requiring significant improvement. Among the recommendations made in addressing this is the provision of education programmes for patients and carers, but not their children. Results reported in this thesis strongly support the need to extend this to patient's children, with nearly 50% reporting not having enough information about their parent's condition.

The current guidelines highlight the need to conduct further research with children of stroke patients in order for their specific needs to be incorporated. A priority must therefore be to continue the early investigations reported in this thesis and by Visser-Meily *et al.* (2005a; b), and thereby draw attention to the impact of parental stroke so that this is incorporated in future revisions.

(8-2-iii) National Clinical Guideline for Multiple Sclerosis: In stark contrast to the discussed guidelines for stroke and PD, the NICE guidelines for multiple sclerosis (National Institute for Health & Clinical Excellence, 2004) do recognise the significant emotional and practical needs of children of PWMS. The document makes clear from the outset that general principles should incorporate support for family and carers. Specifically the document states:

'Family members (including any schoolchildren) living in the same house as the person with MS, and any family members delivering substantial support even if living elsewhere, should be supported by:

- *Asking about their physical and emotional health and well-being, especially in the case of children aged 16 years or less, and offering advice and referring on for additional support if necessary*
- *Providing them with general factual information about MS; this should only be extended to include more specific information related to the person with MS with the permission of that person*
- *Ensuring that they are willing to undertake support of personal activities of daily living (such as dressing and toileting), are safe and competent at such tasks, and that the person with MS is happy for them to provide such assistance*
- *Informing them about social services carer assessment and support procedures'*

Other areas related specifically to children that are considered include the extent to which the PWMS is able to care for their children, based on their ability to perform activities of daily living. Considerable emphasis is placed on appropriate training of family members who assist the PWMS. Among those areas considered are training in equipment and adaptations to assist the PWMS, and the insertion of percutaneous endoscopic gastronomy tubes to assist with swallowing difficulties.

This focus on the emotional and practical needs of children is not apparent in the clinical guidelines for PD and stroke, and from the data presented in this thesis it is clear that such an approach needs to be considered with all three conditions. The guidelines for MS do, however, fail to consider some aspects presented here, although as new findings this is unsurprising. For example the heightened impact of parental illness on those children without the support of siblings is not considered.

Neither is the inferior emotional development of children of PWMS as demonstrated by results relating to adolescent attachment. It must be emphasised that this is purely a function of the levels of research undertaken. As evidence based, and in light of their being little previous data on children of parents with PD and no data on children of stroke patients, it is unsurprising that the relevant guidelines fail to recognise the needs of the children of these patients. This emphasises the need for further research and recognition of the impact of parental illness.

(8-2-iv) The National Service Framework: Research presented in this thesis supports and fits well with the UK governments National Service Framework (NSF) for Long-term Conditions (Department of Health, 2005). This is an overarching document that focuses on neurological conditions with a view to implementing a 'structured and systematic approach to delivering treatment and care', and emphasising a 'person-centred approach for everyone who uses health and social care services'. The framework sets out 11 'quality requirements' (QR), one of which is the support of carers and family members of patients. This QR is further broken down into a number of sub-sections with recognition of the vital role that family and friends of patients play in the 'progress, well-being and quality of life of the person'.

Amongst those elements of the QR relevant to this thesis is acknowledgement of the deleterious affect parental neurological conditions can have on children, and the need to ensure children do not fall into the role of carers. The QR goes on to emphasise the adjustments families may need to make in light of behavioural and cognitive changes in the patient, and that assistance might be required in doing so, with a 'whole family approach', including children, being recommended. The document also provides 'evidence-based markers of good practice', and amongst these is the recommendation that services provide support for children of patients. As is recognised in his ministerial forward by the Secretary of State for Health, 'change cannot happen overnight' and as such the NSF has a targeted implementation period of 10 years. Much of the data reported in this thesis is of relevance to this document, and the points discussed below might provide a starting point for how some of the support recommended for children in the NSF might be provided.

(8-2-v) Clinical Guidelines for Mental Health: Data presented in this thesis highlight the emotional well-being of both adolescent and adult children when confronted with parental illness. The British Government has recognised the

importance of mental health in primary care in their national service framework (Department of Health, 1999) and also specifically in children and adolescents (Meltzer *et al.*, 2000). This is further highlighted in recent guidelines published by NICE for the treatment of depression in children and adolescents (National Institute for Health & Clinical Excellence, 2005).

Recommendations in the NICE guideline include the provision of appropriate therapy and medication, and also the need to address parent's mental health needs if children or adolescent's depressive symptoms are to be effectively treated. As has been reported in other studies, the key to the effective treatment of depression remains its recognition and treatment in both adolescents (Rowe *et al.*, 2004) and adults (Kessler *et al.*, 1999). The NICE guidelines reiterate this in recommending that 'healthcare professionals in primary care, schools and other relevant community settings should be trained to detect symptoms of depression, and to assess children who may be at risk of depression'.

In disseminating results from this thesis it is hoped that children confronted with parental illness, be they young or adult, are recognised as being at increased risk of mental health problems, as is supported by the levels of self-reported depression in this and other studies (i.e. Yahav *et al.*, 2007; Steck *et al.*, 2006). It is also a priority that this is included in future clinical guidelines, such as PD and stroke, where the mental health of patient's children is currently unrecognised. Given that these results are consistently found in those studies that do consider the psychological well-being of children of affected parents, this also appears an important consideration in the assessment of conditions where the mental health of children has to date been ignored, such as arthritis and chronic back pain.

(8-3) Implications for service providers: A starting point for any organisation or body involved in the management of chronic or acute neurological conditions should be the provision of appropriate information for the children of patients as and when they feel the need to access it. This information should be at a developmentally appropriate level for children as identified by Cross (1999) in a previous study of children of PWMS. As stated in chapter 6 and 7, a significant number of the children who took part in this study reported not having enough information about their parent's condition. That is not to say that children, young or old, should be bombarded with literature at the time of their parent's diagnosis. It became clear at the key informant interview phase that some children had enough information 'for the

time being', but may require more in the future. The key for the medical profession and support charities is to ensure this information is available, and that children can access it. The use of modern technology such as the Internet, including notice-boards and chat-rooms, such as that provided by the American Parkinson's Association and the MS societies in America and Canada, may be particularly appropriate for younger children as a way of allowing them to access information in a relatively informal and impersonal manner. It may well be that some younger, and indeed older children find the prospect of making contact with support charities via telephone a daunting one regardless of confidentiality policies.

A finding of clinical relevance is the provision of practical support and guidance for children of affected parents. The desire by many children to have guidance in how to care for their affected parent exposes a gap in what is currently available. As a starting point focus groups need to be conducted with children from all three parental illness groups to explore what aspects of their parent's condition they feel they need support and guidance in. It must, however, remain a priority to ensure that children, particularly adolescents, are not lead down the path of being 'trained' or expected to care for their parent, and effectively become 'young carers'. A significant body of literature now exists on children taking on this role, and its adverse affects on social development are well documented (Becker *et al.*, 1998).

(8-4) Directions for future research: The following section attempts to identify some key areas for future research that should facilitate further recognition of the impact of parental illness, and help in developing practical strategies to assist in its management. Finally, the relevance and further development of the PIIS-R is briefly discussed.

(8-4-i) The need for longitudinal study: There is a limit to what can be concluded from a cross-sectional design such as that employed in this study. Longitudinal study is required in order in order to assess families over time and follow the process of physical, emotional, social and practical adaptation. It is here that the differences between chronic and acute parental conditions can be assessed as the disease trajectory unfolds. It could be hypothesised that the immediate impact on children of parental stroke may ease over time, dependent on the degree of subsequent cognitive and functional recovery. Conversely with chronic progressive conditions such as Parkinson's and MS, it is likely that the impact on the child and the pressures they face, such as the decision to leave home, will become more profound.

It is important to note that not all children with an affected parent report negative outcomes (Alexander *et al,* 2002; Mukherjee, 2002b; Blackford, 1992), and longitudinal study could identify factors implicated in children's positive response to their parent's condition. Conversely, longitudinal study would provide an avenue for the development of interventions, as well as the identification of those families and illness groups most 'at risk'. Results from this study suggest children who live closest to the affected parent and those without the support of siblings fall into this category, and children of PwMS appear particularly affected emotionally by their parent's condition. Currently, however, there appears to be no longitudinal data relating to PwMS. The current work of researchers such as Yahav (2005; 2007), which addresses a number of previous weaknesses in sample sizes and employment of control groups, would be enhanced further still through longitudinal investigation. Only in the assessment of parental affective disorder has longitudinal study made a significant contribution to the literature (i.e. Beardslee *et al.*, 1993; Weisman *et al.*, 1997), and this should remain an important priority for those investigating alternative conditions.

(8-4-ii) Investigating alternative parental conditions: The need to investigate the impact of parental illness should not stop with those groups reported in this thesis. Charities such as the Parkinson's Disease Society recognise that their emphasis on supporting children of parents is limited, whilst some groups such as the Spinal Cord Injury Association provide no support as no specific research has been conducted. The need to conduct research with children who have parents with spinal cord injury or traumatic brain injury has already been identified by the author, and preliminary investigations into its viability have been made. Ultimately the expansion over time to any parental condition that has potentially harmful affects to a child's social and emotional development and well-being could be a target for such investigation. The need to continue research with newly investigated conditions is also paramount. Research with groups such as stroke (Visser-Meily *et al.*, 2005a;b) and inflammatory bowel disease (IBD) (Mukherjee *et al.,* 2002a;b) has to date considered only a narrow range of variables, and such parental conditions require wider assessment in relation to their impact on the child.

(8-4-iii) Conducting research with younger children: There is a further need to assess the impact of parental illness on younger children, and not solely adolescents and adult children as reported in this thesis. Particularly with a condition such as MS,

where the average age of onset is relatively young, the implications for children below the age of 11 are likely to be just as profound, if not more so, than for older children. Indeed a number of families expressed a wish for their children under the age of 11 to take part in this study. Support groups, such as that provided for younger children of parents with cancer as reported by Greening (1999), may well be a valid tool in helping younger children understand what is happening to their parent. Here both parents and children are encouraged to develop positive coping strategies and discuss their fears in a supportive environment, as well as giving parents an insight into how children might perceive their illness.

(8-4-iv) Relevance and further development of the PIIS-R: The development of a scientifically sound research tool such as the PIIS-R is important for this field of research. It allows for a standardised instrument to be administered to adolescent and adult children of varying ages across a range of conditions. Additionally, it may potentially avoid some of the conflicting results produced by the measurement of different variables and the administration of a variety of different measures, as can be seen in the range of methodologies incorporated in the studies reviewed in chapter 1. The revised Parental Illness Impact Scale may benefit from further refinement following administration to larger samples, but currently shows strong psychometric properties. With longitudinal data further properties such as predictive validity and sensitivity to change can be assessed, and the instrument will be made available to other investigators should they wish to incorporate it in their research.

(8-5) Limitations of study:

(8-5-i) Design: Data presented in this thesis is cross-sectional in nature and presents an assessment at one point in time. As previously discussed, longitudinal data is required to make a more detailed evaluation of the well-being of not just children of PWP, PWMS, and stroke patients, but also the majority of those parental conditions discussed in chapter one. The sample sizes employed are adequate in all but the stroke group, and as previously stated this remains a challenge for future research. The recruitment of patients, their spouses and children following the trauma of an acute incident is a highly sensitive and ethical issue. This is often reflected in small sample sizes, as seen in studies relating to parental SCI (e.g. Alexander *et al.*, 2002; Westgren & Levi 1994), but one that can be addressed as demonstrated by the research of Visser-Meily *et al.* (2005a;b) with children of stroke patients. The small stroke group employed in this thesis has implications for statistical power, and there may be further differences between the three groups studied that there was

insufficient power to detect. A number of the analyses were also correlational and as such do not establish causation, but results do start as a reference point for further research.

The data reported incorporates both qualitative and quantitative methodology. Qualitative methodology is limited in that it does not allow generalisations to be made about the target population, as seen in previous studies of children of PWP (Grimshaw, 1991), and parents with IBD (Mukherjee *et al.,* 2002b). The early qualitative studies reported in chapter four were used as a means of developing the PIIS, and not to make generalisations regarding the impact of parental illness. The later quantitative studies incorporated a postal mode of administration using self-report instruments, and it is recognised that there are weaknesses inherent in such a design. There are well documented limitations in the use of questionnaires, in relation not only to the biases of self-report, but also practical considerations. For example, Erling (1999) refers to the need for younger participants to be allowed undisturbed time alone in which to complete their questionnaires, and also the need to respect a child's integrity, just as one would with adult participants. This is clearly beyond the researcher's direct control in a postal study such as that reported here. It is therefore unclear as to how much influence parents may have had over younger people's responses, and this should be considered when drawing any conclusions from the results.

(8-5-ii) Control groups: The recruitment of control groups were initially proposed for this study, but this had to be revised due to ethical considerations. There is therefore a limit to what can be concluded from the results in the absence of comparative data from adolescent and adult children with healthy parents. Few studies have incorporated control groups to date, although some recent studies, such as those investigating adolescent children of parents with cancer (Harris & Zakowski 2003), and adolescent children of PWMS (Yahav *et al.*, 2005, 2007) have done so. This is another challenge for future research in this field. In the absence of control groups it is difficult to draw firm conclusions on a number of issues which are of importance when assessing the impact of parental illness. As an example, results demonstrate clear differences in perceived burden of daily help between those, mainly younger children who remain in the family home, and their largely older counterparts who have left. This is, however, difficult to quantify. As identified by Schrag *et al.* (2004), it may well be that these younger children participate more in domestic routines than children without a chronically ill parent, or alternatively they may be at a particular

stage of adolescence where any parental demand placed upon them is met with a certain degree of resentment. Conversely, do adult children perceive their helping as less of a burden out of a well-documented sense of duty (MacCarthy, 1997), and greater recognition and acceptance of changing family roles? In the absence of control groups questions such as these are difficult to answer.

(8-5-iii) Selection bias: This was a self-selected sample due to the mode of recruitment, and therefore is unlikely to be representative of the target population, as is indeed reflected in the socio-economic make-up of the sample. It is acknowledged that there will therefore be a degree of bias in the results. There remain further important demographic factors and groups that need to be addressed in a comprehensive examination of factors influencing the QoL of children with a chronically ill parent. The need to examine different cultures in relation to studies such as these is an important issue (Grimshaw, 1991). Although ethnic data was obtained for this study, 98% of participants were of white origin, which did not allow for analysis by ethnicity, and this again remains a challenge for future research. Charitable organisations such as the Parkinson's Disease Society recognise that their efforts to engage with ethnic minorities have been slow, whilst at the same time recognising that different cultures may require very different support (Parkinson's Disease Society, 2004). This is particularly so for those cultures where a far greater emphasis is placed on the social support network of the family. A comparison between ethnic minority groups and their support needs, and those of more individualised Western cultures would be an informative line of research.

A further, and likely highly significant group not assessed as part of this research, are single-parent families where the parent is chronically ill, this being of particular relevance to the caring role played by children (Becker *et al.*, 1998). The importance of investigating this group is further highlighted by research that has shown that child and adolescent rates of mental disorder are twice that in single parent families when compared with two parent families (Meltzer *et al.*, 2000).

(8-6) Closing comments: Results presented in this thesis serve to highlight the potential impact parental illness can have on both adolescent and adult children, and, if affected, that their needs must not go unrecognised. The development of a scientifically sound measurement tool specifically to assess this allows for further investigation with those groups reported in this thesis, as well as with children affected by other parental conditions. Future research must consider younger

children although methodological hurdles will need to be considered and overcome. The development of effective interventions, information resources, and evidence-based guidelines, all of which may need to differ dependent on the parental condition, will require longitudinal study. It is this that should become a priority if we are to adequately meet the needs of children touched by the effects of parental illness.

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Appendix A: Parental Illness Impact Scale Revisions and Final Instrument

Instructions: *This questionnaire is divided into a number of different sections. Please **answer every question** by placing a tick in the box that corresponds most closely to how you feel. If you are unsure about an answer please give the **best answer you can**.*

The help you give

		All of the time	Most of the time	Some of the time	A little of the time	None of the time
1	Do you feel you do more chores around the house because one of your parents has PD than you otherwise would?					
2	Do you do household chores (i.e. cooking, cleaning, shopping) on a regular basis?					
3	Do you do such chores as and when they need to be done?					
4	Do you discuss doing these household chores with all of the family?					
5	Do you help with the personal care (for example bathing, dressing) of your parent with PD?					
6	Do you feel that your parent with PD depends on **you** at all because of their illness?					
7	If you have brothers or sisters, do you feel that you give more help than them?					
8	Do you think that PD affects your family life and routine?					
9	Do you feel there is a limit to the amount of help your parents **like** you to give?					
10	Do you negotiate which household tasks you undertake?					
11	Does your **well** parent ever indicate what help is needed?					

		Every day	Every week	Fort-nightly	Every month	Never
12	How often are you involved in daily household chores in your parents' home?					
13	How often do you help with the personal care of your parent with PD?					

Your relationship with your parent with Parkinson's disease

		All of the time	Most of the time	Some of the time	A little of the time	None of the time
14	Do you feel that your parent with PD has difficulty spending time with you or getting involved in activities with you?					
15	Do you feel that your parent with PD has difficulty talking to you?					
16	Do you think that helping to care for your parent with PD has changed your relationship with them?					
17	Do you feel that you and your parent with PD understand each other?					
18	How often do you think that any problems you may have had with your parent with PD are due to their illness rather than anything else?					
19	Do you ever take advantage if your parent with PD is unable to control your behaviour?					
20	Do you feel that you understand the feelings of your parent with PD **less** than the feelings of your well parent?					
21	Do you feel that any problems you have talking with your parent with PD make you feel less close to them?					
22	Do you feel resentful about any changes in your parent's behaviour as a result of PD, such as impatience?					
23	Do you feel you have more responsibility because of your parent's PD?					
24	Do you feel that any increase in responsibility due to your parent's PD is a burden?					
25	Do you think your parent with PD feels that their illness affects **your** independence?					

		Every day	Every week	Fort-nightly	Every month	Never
26	How often do you and your parent with PD do something together (i.e. going out together, watching television)?					
27	How often do you and your **well parent** do something together?					
28	How often do you have problems with your parent with PD?					

Your own well-being

		All of the time	Most of the time	Some of the time	A little of the time	None of the time
29	Would you say that your general health is good?					
30	Do you feel that your parent's PD affects your performance at school?					
31	Do you feel that your parents PD affects the time you spend on social activities?					
32	Do you feel that your parent's PD has affected your **relationships** with friends?					
33	Do you feel your parent's PD affects the **amount of time** you spend with friends?					
34	Do you have difficulty explaining PD to your friends?					
35	Do you feel you are closer to your friends due to your parent's PD?					
36	Do you find it difficult to deal with your friends' fear of PD?					
37	Do you feel embarrassed talking to friends about PD?					

		Every week	Every month	Every third month	Every sixth month	Never
38	Since your parent with PD has been unwell how often do **you** visit your doctor or other health-care professionals for **your** health?					

		Every day	Every week	Fort-nightly	Every month	Never
39	How often do you spend time with friends **out of school hours**?					

Your feelings

		All of the time	Most of the time	Some of the time	A little of the time	None of the time
40	Do you feel that you have developed a greater understanding, knowledge and acceptance of your parent's PD as you have grown older?					
41	Do you feel embarrassed by the effects of PD on your parent?					
42	Do you feel more worried as you grow up?					
43	Do you feel uncertain about the future because of your parent's PD?					
44	Do you feel that your own future may be different than it otherwise might have been because of your parent's PD?					
45	Do you feel worried about your own opportunities for personal development as a result of your parent's PD?					
46	Do you feel that your parent's PD affects **your independence now**?					
47	Do you think that your parent's PD will affect **your independence in the future**?					
48	Do you feel that you have less material things (for example money, possessions) because of your parents PD?					
49	Do you think that living in the family home is more difficult now than before your parent with PD became unwell?					
50	Do you feel that your parent's PD has an impact on **their** daily life?					
51	Do you feel that your parent's PD has an impact on the life of your **well** parent?					

		Every day	Every week	Fort-nightly	Every month	Never
52	How often do **you** do activities (for example hobbies) without your parents?					

		Every week	Every month	Every third month	Every sixth month	Never
53	How often do you go away **without** your parents (for example holidays or staying with friends and relatives)?					

Please answer YES or No to these questions

		YES	NO
54	Do you feel you have all the information you need about PD?		
55	Do you feel you know enough about what will happen in the future to your parent with PD?		
56	Would having more information about PD make you feel less uncertain and insecure?		
57	Do you feel that there is somebody you can talk to about PD if you want to?		
58	Does your parent with PD talk to you about the illness?		
59	Do people outside of your family ever talk to you about PD?		
60	Does talking to people outside of your family help you to understand more about PD?		
61	Does talking about PD help you with some or any of the fears you may have about it?		
62	Does what you know now mean that you can understand why your parent with PD might have difficulties with their daily routine?		
63	Do you just rely on your parents for information about PD?		
64	Would you like the opportunity to have counselling?		

65	Would it help you to have training in how to give practical care?		
66	Do you feel it helps to have contact with other people in similar circumstances to you (for example through the Parkinson's Disease Society)?		
67	Is outside help available in caring for your parent with PD?		
68	Do you think more help (for example meals on wheels, physiotherapy) should be given by health services in the care of your parent with PD?		
69	Do you feel it would help **you** if you were able to talk to local services about any help provided to your parent with PD?		
70	Do you feel it is a normal part of a young persons life to be involved in maintaining the household (i.e. housework, errands, shopping, looking after brothers and sisters?		
71	Do you think that you have grown up more quickly as a result of your parent's PD?		
72	Do you feel that you **have** to care for / help your parent with PD?		
73	Do you think that your parent's PD has affected **your** health?		
74	Did you experience 'difficult feelings' when you learnt about your parent's PD?		
75	Does your parent's PD influence you in making a decision to leave home?		

Are there any other important areas of your life affected by your parent's Parkinson's disease that we have not covered? If so, please say which areas:

Appendix A-ii: PIIS ages 18+, version 1

Instructions: *This questionnaire is divided into a number of different sections. Please* ***answer every question*** *by placing a tick in the box that corresponds most closely to how you feel. If you are unsure about an answer please give the* ***best answer you can.***

The help you give

		All of the time	Most of the time	Some of the time	A little of the time	None of the time
1	Do you feel you are more involved in the running of your parents home due to PD than you otherwise would be?					
2	Are you involved in your parents' household routines (i.e. cooking, cleaning, shopping) on a regular basis?					
3	Do you take on such routines as and when they need to be done?					
4	Do you discuss doing these household routines with all of the family?					
5	Do you help with the personal care (for example bathing, dressing) of your parent with PD?					
6	Do you feel that your parent with PD is dependent on you to some extent as a result of their illness?					
7	If you have brothers or sisters, do you feel that you give more help than them?					
8	Do you think that PD affects **your own** family life and routine?					
9	Do you feel there is a limit to the amount of help your parents **like** you to give?					
10	Do you negotiate which of your parents' household routines you undertake?					
11	Does your **well** parent ever indicate what help is needed?					

		Every day	Every week	Fort-nightly	Every month	Never
12	How often are you involved in daily household chores in your parents' home?					
13	How often do you help with the personal care of your parent with PD?					

Your relationship with your parent with Parkinson's disease

		All of the time	Most of the time	Some of the time	A little of the time	None of the time
14	Do you feel that your parent with PD has difficulty spending time with you or engaging in activities with you?					
15	Do you feel that your parent with PD has difficulty communicating with you?					

		All of the time	Most of the time	Some of the time	A little of the time	None of the time
16	Do you think that helping to care for your parent with PD has changed your relationship with them?					
17	Do you feel that you and your parent with PD understand each other?					
18	How often do you think that any problems you may have had with your parent with PD are due to their illness rather than anything else?					
19	Do you ever use your parent's PD as an excuse for any poor behaviour of your own?					
20	Do you feel that you understand the feelings of your parent with PD **less** than the feelings of your well parent?					
21	Do you feel that any problems you have communicating with your parent with PD make you feel less close to them?					
22	Do you feel resentful about any changes in your parent's behaviour as a result of PD, such as impatience?					
23	Do you feel an increased sense of responsibility due to your parent's PD?					
24	Do you view any increase in responsibility due to your parent's PD as a burden?					
25	Do you think your parent with PD feels that their illness affects **your** independence?					

		Every day	Every week	Fort-nightly	Every month	Never
26	How often do you and your parent with PD engage in leisure activities (for example going out together, watching television)?					
27	How often do you and your **well parent** engage in leisure activities together?					
28	How often do you experience difficulties in your relationship with your parent with PD?					

Your own well-being

		All of the time	Most of the time	Some of the time	A little of the time	None of the time
29	Would you say that your general health is good?					
30	Do you feel that your parent's PD affects your performance in for example your work or education?					
31	Do you feel that your parents PD affects the time you spend on social activities?					
32	Do you feel that your parent's PD has affected your **relationships** with friends?					
33	Do you feel your parent's PD affects the **amount of time** you spend with friends?					

		All of the time	Most of the time	Some of the time	A little of the time	None of the time
34	Do you have difficulty explaining the nature of PD to your friends?					
35	Do you feel you have a closer relationship with friends due to your parent's PD?					
36	Do you experience difficulties in dealing with your friends' fear of PD?					
37	Do you feel embarrassed talking to friends about PD?					

		Every week	Every month	Every third month	Every sixth month	Never
38	Since your parent's diagnosis how often have **you** visited your doctor or other health-care professionals for **your** health in the last year?					

		Every day	Every week	Fort-nightly	Every month	Never
39	How often do you spend time with friends?					

Your feelings

		All of the time	Most of the time	Some of the time	A little of the time	None of the time
40	Do you feel that you have developed a greater understanding, knowledge and acceptance of your parent's PD as you have grown older?					
41	Do you feel embarrassed by the effects of PD on your parent?					
42	Do you feel more worried as you grow older?					
43	Do you feel uncertain about the future because of your parent's PD?					
44	Do you feel that your own future may be different than it otherwise might have been because of your parent's PD?					
45	Do you feel concerned about your own opportunities for personal development as a result of your parent's PD?					
46	Do you feel that your parent's PD affects **your independence now**?					
47	Do you think that your parent's PD will affect **your independence in the future**?					
48	Do you feel that your parent's PD has affected your material well being (for example finances, possessions)?					
49	Do you view living in the family home with a parent with PD as more difficult than before the illness was apparent?					

		All of the time	Most of the time	Some of the time	A little of the time	None of the time
50	Do you feel that your parent's PD has an impact on **their** daily life?					
51	Do you feel that your parent's PD has an impact on the life of your **well** parent?					

		Every day	Every week	Fort-nightly	Every month	Never
52	How often do you pursue activities of an independent nature, for example hobbies?					

		Every week	Every month	Every third month	Every sixth month	Never
53	How often do you take a holiday or short break **away from your parent** with PD?					

Please answer YES or No to these questions

		YES	NO
54	Do you feel you have all the information you need about PD?		
55	Do you feel you know enough about what will happen in the future to your parent with PD?		
56	Would having more information about PD lessen feelings such as uncertainty and insecurity?		
57	Do you feel that there is somebody available for you to talk to about PD if you wish to do so?		
58	Does your parent with PD talk to you about the illness?		
59	Do people outside of your family ever talk to you about PD?		
60	Does talking to people outside of your family help you to understand more about PD?		
61	Does talking about PD help you to address some or any of the fears you may have about it?		
62	Does your current knowledge enable you to understand why your parent with PD might experience difficulties with their daily routine?		
63	Do you rely solely on your parents for information about PD?		
64	Would you like the opportunity to have counselling regarding your parent's PD?		
65	Would it help you to have training in how to give practical care?		

		YES	NO
66	Do you feel it helps to have contact with other people in similar circumstances to yourself (for example through the Parkinson's Disease Society)?		
67	Is outside help available in caring for your parent with PD?		
68	Do you think that more help (for example meals on wheels, physiotherapy) should be provided by health services in the care of your parent with PD?		
69	Do you feel it would helpful to **you** if you had some influence over the services provided to your parent with PD?		
70	Do you feel it is a normal part of adult life to be involved in maintaining your parents' home?		
71	Do you think that you have matured more quickly as a result of your parent's PD?		
72	Do you feel that you **have** to care for / help your parent with PD?		
73	Do you think that your parent's PD has affected **your** general well being?		
74	Did you experience 'difficult feelings' when your parent's PD was diagnosed?		
75	Does (did) your parent's PD influence your decision to leave home?		

Are there any other important areas of your life affected by your parent's Parkinson's disease that we have not covered? If so, please say which areas:

Instructions: *This questionnaire is divided into a number of different sections. Please **answer every question** by placing a tick in the box that corresponds most closely to how you feel. If you are unsure about an answer please give the **best answer you can.***

Social development, independence and responsibility

		All the time	Often	Some-times	Rarely	Never
1	Do you feel your parent's PD affects the **amount of time** you spend with friends?					
2	Do you feel that your parent's PD has affected your **relationships** with friends?					
3	Do you feel that your parents PD affects the time you spend on social activities?					
4	Are you ever worried about your own opportunities for personal development because of your parent's PD?					
5	Do you feel that your parent's PD affects **your independence now**?					
6	Do you ever feel that any increase in responsibility due to your parent's PD is a burden?					
7	Does PD affect your family life and routine?					
8	Do you think that helping to care for your parent with PD has changed your relationship with them?					
9	Do you feel that your parent with PD depends on **you** because of their illness?					
10	Do you think that your parent's PD will affect **your independence in the future**?					
11	Do you ever feel that your parent's PD affects your schoolwork?					
12	Do you feel there is a limit to the amount of help your parents **like** you to give?					
13	Do you feel you have more responsibility because of your parent's PD?					

Burden of daily help

		All the time	Often	Some-times	Rarely	Never
14	Do you feel you have to do more chores around the house because one of your parents has PD?					
15	Do you do household chores (i.e. cooking, cleaning, shopping) on a regular basis?					

		All the time	Often	Some-times	Rarely	Never
16	How often do you discuss doing these household chores with all of the family?					
17	Do you do such chores as and when they need to be done?					
18	If you have brothers or sisters, do you feel that you give more help than them?					
19	Do you negotiate which household tasks you undertake?					

		Every day	Every week	Every month	Rarely	Never
20	How often would you say you are you involved in daily household chores?					

Communication and understanding

		All the time	Often	Some-times	Rarely	Never
21	Do you feel that your parent with PD has difficulty spending time with you or getting involved in activities with you?					
22	Do you ever feel that your parent with PD has difficulty talking to you?					
23	Do you feel that you and your parent with PD understand each other?					
24	How often do you think that any problems you may have had with your parent with PD are due to their illness rather than anything else?					
25	Do you feel that you understand the feelings of your parent with PD **less** than the feelings of your well parent?					
26	Do any problems you have talking with your parent with PD ever make you feel less close to them?					
27	Do you ever feel resentful about any changes in your parent's behaviour as a result of PD, such as impatience?					
28	Are you embarrassed by the effects of PD on your parent?					

		Every day	Every week	Every month	Rarely	Never
29	How often do you have problems with your parent with PD?					

Friends' Reactions

		All the time	Often	Some-times	Rarely	Never
30	Do you have difficulty explaining PD to your friends?					
31	Do you find it difficult to deal with your friends' fear of PD?					
32	Are you ever embarrassed talking to friends about PD?					

Impact on personal future

		All the time	Often	Some-times	Rarely	Never
33	Do you feel more worried as you grow up?					
34	Do you ever feel uncertain about the future because of your parent's PD?					
35	Do you feel that your own future may be different than it otherwise might have been because of your parent's PD?					

Impact on family functioning

		All the time	Often	Some-times	Rarely	Never
36	Do you ever think that living in the family home is more difficult now than before your parent with PD became unwell?					
37	Do you feel that your parent's PD has an impact on **their** daily life?					
38	Do you feel that your parent's PD has an impact on the life of your **well** parent?					

We would like to know a little more about you so that we can try and work out what things we might be able to do to help you. ***Please answer YES or No to these questions.***

		YES	NO
39	Would you say you have all the information you need about PD?		
40	Do you feel you know enough about what will happen in the future to your parent with PD?		

		YES	NO
41	Would having more information about PD make you feel less uncertain and insecure?		
42	Do you feel that there is somebody you can talk to about PD if you want to?		
43	Does your parent with PD talk to you about the illness?		
44	Do people outside of your family ever talk to you about PD?		
45	Does talking to people outside your family help you to understand more about PD?		
46	Does talking about PD help you with some or any of the fears you may have about it?		
47	Does your knowledge of PD mean you can understand why your unwell parent might have difficulties with their daily routine?		
48	Do you just rely on your parents for information about PD?		
49	Would you like the opportunity to have counselling?		
50	Would it help you to have training in how to give practical care?		
51	Do you feel it helps to have contact with other people in similar circumstances to you (for example through the Parkinson's Disease Society)?		
52	Is outside help available in caring for your parent with PD?		
53	Do you think more help (for example meals on wheels, physiotherapy) should be given by health services in the care of your parent with PD?		
54	Do you feel it would help **you** if you were able to talk to local services about any help provided to your parent with PD?		
55	Do you feel it is a normal part of a young persons life to be involved in maintaining the household, i.e. housework, shopping, looking after brothers and sisters?		
56	Do you think that you have grown up more quickly as a result of your parent's PD?		
57	Do you feel that you **have** to care for / help your parent with PD?		
58	Do you think that your parent's PD has affected **your** health?		
59	Did you experience 'difficult feelings' when you learnt about your parent's PD?		
60	Do you think your parent's PD will influence you in making a decision to leave home?		

Are there any other important areas of your life affected by your parent's Parkinson's disease that we have not covered? If so, please say which areas:

Appendix A-iv: PIIS ages 18+, version 2

Instructions: *This questionnaire is divided into a number of different sections. Please **answer every question** by placing a tick in the box that corresponds most closely to how you feel. If you are unsure about an answer please give the **best answer you can**.*

Social development, independence and responsibility

		All the time	Often	Some-times	Rarely	Never
1	Do you feel your parent's PD affects the **amount of time** you spend with friends?					
2	Do you feel that your parent's PD has affected your **relationships** with friends?					
3	Do you feel that your parents PD affects the time you spend on social activities?					
4	Do you feel concerned about your own opportunities for personal development as a result of your parent's PD?					
5	Do you feel that your parent's PD affects **your independence now**?					
6	Do you view any increase in responsibility due to your parent's PD as a burden?					
7	Do you think that PD affects **your own** family life and routine?					
8	Do you think that helping to care for your parent with PD has changed your relationship with them?					
9	Do you feel that your parent with PD is dependent on you to some extent as a result of their illness?					
10	Do you think that your parent's PD will affect **your independence in the future**?					
11	Do you feel that your parent's PD affects your performance in for example your work or education?					
12	Do you feel there is a limit to the amount of help your parents **like** you to give?					
13	Do you feel an increased sense of responsibility due to your parent's PD?					

Burden of daily help

		All the time	Often	Some-times	Rarely	Never
14	Do you feel you are more involved in the running of your parents' home due to PD than you otherwise would be?					
15	Are you involved in your parents' household routines (i.e. cooking, cleaning, shopping) on a regular basis?					
16	Do you discuss doing these household routines with all of the family?					
17	Do you take on such routines as and when they need to be done?					

		All the time	Often	Some-times	Rarely	Never
18	If you have brothers or sisters, do you feel that you give more help than them?					
19	Do you negotiate which of your parents' household routines you undertake?					

		Every day	Every week	Every month	Rarely	Never
20	How often would you say you are you involved in daily household chores in your parents' home?					

Communication and understanding

		All the time	Often	Some-times	Rarely	Never
21	Do you feel that your parent with PD has difficulty spending time with you or engaging in activities with you?					
22	Do you ever feel that your parent with PD has difficulty communicating with you?					
23	Do you feel that you and your parent with PD understand each other?					
24	How often do you think that any problems you may have had with your parent with PD are due to their illness rather than anything else?					
25	Do you feel that you understand the feelings of your parent with PD **less** than the feelings of your well parent?					
26	Do any problems you have talking with your parent with PD ever make you feel less close to them?					
27	Do you ever feel resentful about any changes in your parent's behaviour as a result of PD, such as impatience?					
28	Are you embarrassed by the effects of PD on your parent?					

		Every day	Every week	Every month	Rarely	Never
29	How often do you experience difficulties in your relationship with your parent with PD?					

Friends' Reactions

		All the time	Often	Some-times	Rarely	Never
30	Do you have difficulty explaining the nature of PD to your friends?					
31	Do you experience difficulties in dealing with your friends' fear of PD?					
32	Are you ever embarrassed talking to friends about PD?					

Impact on personal future

		All the time	Often	Some-times	Rarely	Never
33	Do you feel more worried as you grow older?					
34	Do you ever feel uncertain about the future because of your parent's PD?					
35	Do you feel that your own future may be different than it otherwise might have been because of your parent's PD?					

Impact on family functioning

		All the time	Often	Some-times	Rarely	Never
36	Do you view living in the family home with a parent with PD as more difficult than before the illness was apparent?					
37	Do you feel that your parent's PD has an impact on **their** daily life?					
38	Do you feel that your parent's PD has an impact on the life of your **well** parent?					

We would like to know a little more about you so that we can try and work out what things we might be able to do to help you. ***Please answer YES or No to these questions.***

		YES	NO
39	Would you say you have all the information you need about PD?		
40	Do you feel you know enough about what will happen in the future to your parent with PD?		
41	Would having more information about PD lessen feelings such as uncertainty and insecurity?		
42	Do you feel that there is somebody available for you to talk to about PD if you wish to do so?		
43	Does your parent with PD talk to you about the illness?		
44	Do people outside of your family ever talk to you about PD?		
45	Does talking to people outside your family help you to understand more about PD?		
46	Does talking about PD help you to address some or any of the fears you may have about it?		
47	Does your knowledge of PD mean you can understand why your unwell parent might have difficulties with their daily routine?		
48	Do you rely solely on your parents for information about PD?		

		YES	NO
49	Would you like the opportunity to have counselling regarding your parent's PD?		
50	Would it help you to have training in how to give practical care?		
51	Do you feel it helps to have contact with other people in similar circumstances to yourself (for example through the Parkinson's Disease Society)?		
52	Is outside help available in caring for your parent with PD?		
53	Do you think more help (for example meals on wheels, physiotherapy) should be provided by health services in the care of your parent with PD?		
54	Do you feel it would be helpful to **you** if you had some influence over the services provided to your parent with PD?		
55	Do you feel it is a normal part of adult life to be involved in maintaining your parents' home?		
56	Do you think that you have matured more quickly as a result of your parent's PD?		
57	Do you feel that you **have** to care for / help your parent with PD?		
58	Do you think that your parent's PD has affected **your** general well being?		
59	Did you experience 'difficult feelings' when your parent's PD was diagnosed?		
60	Does (did) your parent's PD influence your decision to leave home?		

Are there any other important areas of your life affected by your parent's Parkinson's disease that we have not covered? If so, please say which areas:

Instructions: *This questionnaire is divided into a number of different sections. Please **answer every question** by placing a tick in the box that describes most closely how you feel. If you are not sure about an answer please give the **best answer you can**. Certain questions might not apply to you. If this is the case please tick the* NA *box provided. This would be the case if, for example, when answering question 33, you have no brothers or sisters.*

SECTION A

	About your health	Excell -ent	Very Good	Good	Fair	Poor
1.	Would you say that, in general, your physical health is:					
2.	Would you say that, in general, emotionally you feel:					
3.	And would you rate your sleep as:					

	How You Feel Inside **How often does your parent's PD make you feel:**	All the time	Often	Some-times	Rarely	Never
4.	Sad or like crying?					
5.	Angry?					
6.	Afraid?					
7.	Nervous?					
8.	Jealous or neglected because of lack of attention?					
9.	Guilty about feeling jealous or neglected?					

	Your Behaviour **How often would you say that due to your parent's PD you:**	All the time	Often	Some-times	Rarely	Never
10.	Argue?					
11.	Are disruptive at home, school or work?					
12.	Lie or cheat?					
13.	Generally behave badly?					

Your Social Life

	How often do you feel that your parent's PD affects:	All the time	Often	Some-times	Rarely	Never
14.	The **amount of time** you spend with friends?					
15.	Your **relationships** with friends?					
16.	The time you spend on social activities?					
17.	Your schoolwork?					

		Every day	Every week	Every month	Rarely	Never
18.	How often do you spend time with friends **out of school hours**?					

Changes in Yourself

	Do you feel:	All the time	Often	Some-times	Rarely	Never
19.	More **mature** as a result of your parent's PD?					
20.	More **understanding and sympathetic** of other peoples' illness and disability as a result of your parent's PD?					
21.	That you **cope** better with difficult problems as a result of your parent's PD?					
22.	That as a result of your parent's PD you are better at **finding ways to deal with problems**?					
23.	More **independent** as a result of your parent's PD?					

Independence and Responsibility

	Would you say that:	All the time	Often	Some-times	Rarely	Never
24.	You feel your parent's PD affects **your independence**?					
25.	You feel you have **more responsibility** because of your parent's PD?					
26.	You feel that any increase in responsibility due to your parent's PD is a **burden**?					
27.	That your parent with PD depends on **you** because of their illness?					
28.	There is a limit to the amount of help your parents **like** you to give?					

At Home

	Do you:	All the time	Often	Some-times	Rarely	Never
29.	Do household chores (i.e. cooking, cleaning, shopping) on a regular basis?					
30.	Feel you do more household chores because one of your parents has PD?					
31.	Do such chores as and when they need to be done?					
32.	Discuss doing these household chores with all of the family?					
33.	Feel you give more help than any brothers and sisters you may have? NA					
34.	Discuss which household tasks you do?					

		Every day	Every week	Every month	Rarely	Never
35.	How often would you say you are you involved in daily household chores?					

You & Your Parent(s)

	Do you feel:	All the time	Often	Some-times	Rarely	Never
36.	Your parent with PD has difficulty **spending time with you or getting involved in activities with you**?					
37.	Your parent with PD has difficulty getting involved specifically in **physical activities** (i.e. sports) with you?					
38.	Your parent with PD has difficulty **talking** to you?					
39.	That you and your parent with PD **understand each other**?					
40.	Any **problems** you may have had with your parent with PD are due to their illness rather than anything else?					
41.	That helping to care for your parent with PD has **changed your relationship** with them?					
42.	That you **have** to help / care for your parent with PD?					
43.	You understand the feelings of your parent with PD **less** than the feelings of your well parent? NA					
44.	That any problems you have talking with your parent with PD make you feel **less close** to them?					
45.	**Resentful** about any changes in your parent's behaviour as a result of PD, such as being impatient?					
46.	**Embarrassed** by the effects of PD on your parent?					

		Every day	Every week	Every month	Rarely	Never
47.	How often do you have problems with your parent with PD?					

You and Your Friends

	How often would you say that you:	All the time	Often	Some-times	Rarely	Never
48.	Have difficulty explaining PD to your friends?					
49.	Find it difficult to deal with your friends' fear of PD?					
50.	Are embarrassed talking to friends about PD?					
51.	Are bullied or made fun of because of your parent's PD?					

		Every day	Every week	Every month	Rarely	Never
52.	How often do you have problems with friends because of your parent's PD?					

Your Future

	Would you say that you:	All the time	Often	Some-times	Rarely	Never
53.	Worry about opportunities for your personal development because of your parent's PD?					
54.	Are concerned that your parent's PD will affect **your independence in the future**?					
55.	Feel your parent's PD will affect when you make a decision to leave home?					
56.	Feel **uncertain** about the future because of your parent's PD?					
57.	Feel that your own future may be different than it otherwise might have been because of your parent's PD?					

Impact on Your family

	Do you feel that:	All the time	Often	Some-times	Rarely	Never
58.	PD affects your family life and routine?					
59.	Living in the family home is more difficult now than before your parent with PD became unwell?	NA				
60.	Having a parent with PD affects your family financially?					
61.	Your parent's PD has an impact on **their** daily life?					
62.	Your parent's PD has an impact on the life of your **well** parent?	NA				
63.	Your parent's PD has an impact on the life of your **whole family**?					

SECTION B: Please answer YES *or* No *to these questions.*

Information for you

		YES	NO
64.	Do you have all the information you need about PD?		
65.	Do you feel you know enough about what will happen in the future to your parent with PD?		
66.	Do you rely just on your parent(s) for information about PD? If no please write below from where else you receive information.		

Support for you

		YES	NO
67.	Do you feel that there is somebody you can talk to about PD if you want to?		
68.	Do you feel you have all the support you need from friends and family?		
69.	Do you have ways to deal with any anger / anxiety you may feel?		
70.	Does your parent with PD talk to you about the illness?		
71.	Would it help to have contact with people in a similar situation (e.g. through the Parkinson's Disease Society)?		

External help for you

		YES	NO
72.	Would it help you to have training in how to care for your parent with PD?		
73.	Do you think it would be helpful if you had the opportunity to have individual counselling?		
74.	Do you think it would help you to have counselling as a family?		

External help for your parents

		YES	NO
75.	Is outside help available in caring for your parent with PD?		
76.	Do you think more help (e.g. meals on wheels, physiotherapy) should be provided to help care for your parent with PD?		
77.	Do you feel it would help **you** if you were able to talk to local services about any help provided for your parent with PD or your well parent?		

Instructions: *This questionnaire is divided into a number of different sections. Please **answer every question** by placing a tick in the box that corresponds most closely to how you feel. If you are unsure about an answer please give the **best answer you can**. Certain questions might not apply to you. If this is the case please tick the* NA *box provided. This would be the case if, for example, when answering question 33, you have no other family members.*

SECTION A

About your health

		Excell -ent	Very Good	Good	Fair	Poor
1.	Would you say that, in general, your physical health is:					
2.	Would you say that, in general, emotionally you feel:					
3.	And would you rate your sleep as:					

How You Feel Inside

	How often does your parent's PD make you feel:	All the time	Often	Some-times	Rarely	Never
4.	Sad or like crying?					
5.	Angry or resentful?					
6.	Afraid?					
7.	Anxious or nervous?					
8.	Jealous or neglected because of lack of contact or attention?					
9.	Guilty about feeling jealous or neglected?					

Your Behaviour

	How often would you say that due to your parent's PD you:	All the time	Often	Some-times	Rarely	Never
10.	Argue?					
11.	Are disruptive at home, college or work?					
12.	Lie or cheat?					
13.	Generally behave badly?					

Your Social Life

	How often do you feel that your parent's PD affects:	All the time	Often	Some-times	Rarely	Never
14.	The **amount of time** you spend with friends?					
15.	Your **relationships** with friends?					
16.	The time you spend on social activities?					
17.	Your performance at college or work?					

		Every day	Every week	Every month	Rarely	Never
18.	How often do you spend time with friends **away from college or work?**					

Changes in Yourself

	Do you feel:	All the time	Often	Some-times	Rarely	Never
19.	You have **developed** further as an individual as a result of your parent's PD?					
20.	More **tolerant and sympathetic** of other peoples' illness and disability as a result of your parent's PD?					
21.	That you **cope** better with difficult problems as a result of your parent's PD?					
22.	That as a result of your parent's PD you are better at **finding ways to deal with problems**?					
23.	More **independent** as a result of your parent's PD?					

Independence and Responsibility

	Would you say that:	All the time	Often	Some-times	Rarely	Never
24.	You feel your parent's PD affects **your independence**?					
25.	You feel you have **more responsibility** because of your parent's PD?					
26.	You feel that any increase in responsibility due to your parent's PD is a **burden**?					
27.	That your parent with PD depends on **you** because of their illness?					
28.	There is a limit to the amount of help your parents **like** you to give?					

At Home

	Do you:	All the time	Often	Some-times	Rarely	Never
29.	Get involved in the daily running of your parents' home (i.e. cooking, cleaning, shopping) on a regular basis?					
30.	Feel you do more household chores because one of your parents has PD?					
31.	Do such chores as and when they need to be done?					
32.	Discuss doing these household chores with all of the family?					
33.	Feel you give more help than other family members? NA					
34.	Negotiate which household tasks you undertake?					

		Every day	Every week	Every month	Rarely	Never
35.	How often would you say you are you involved in the daily running of your parents' home?					

You & Your Parent(s)

	Do you feel:	All the time	Often	Some-times	Rarely	Never
36.	Your parent with PD has difficulty **spending time with you or getting involved in activities with you**?					
37.	Your parent with PD has difficulty getting involved **specifically in physical activities** with you?					
38.	Your parent with PD has difficulty **talking** to you?					
39.	That you and your parent with PD **understand each other**?					
40.	Any **problems** you may have had with your parent with PD are due to their illness rather than anything else?					
41.	That helping to care for your parent with PD has **changed your relationship** with them?					
42.	That you **have** to help / care for your parent with PD?					
43.	You understand the feelings of your parent with PD **less** than the feelings of your well parent? NA					
44.	That any problems you have talking with your parent with PD make you feel **less close** to them?					
45.	**Resentful** about any changes in your parent's behaviour as a result of PD, such as impatience?					
46.	**Embarrassed** by the effects of PD on your parent?					

		Every day	Every week	Every month	Rarely	Never
47.	How often do you have problems with your parent with PD?					

You and Your Friends

	How often would you say that you:	All the time	Often	Some-times	Rarely	Never
48.	Have difficulty explaining PD to your friends?					
49.	Find it difficult to deal with your friends' fear of PD?					
50.	Are embarrassed talking to friends about PD?					
51.	Are bullied or taunted because of your parent's PD?					

		Every day	Every week	Every month	Rarely	Never
52.	How often do you have problems with friends because of your parent's PD?					

Your Future

	Would you say that you:	All the time	Often	Some-times	Rarely	Never
53.	Worry about opportunities for your personal development because of your parent's PD?					
54.	Are concerned that your parent's PD will affect **your independence in the future**?					
55.	Feel your parent's PD will influence when you make a decision to leave home? NA					
56.	Feel **uncertain** about the future because of your parent's PD?					
57.	Feel that your own future may be different than it otherwise might have been because of your parent's PD?					

Impact on Your family

	Do you feel that:	All the time	Often	Some-times	Rarely	Never
58.	PD affects your family life and routine?					
59.	Living in the family home is more difficult now than before your parent with PD became unwell? NA					
60.	Having a parent with PD affects your family financially?					
61.	Your parent's PD has an impact on **their** daily life?					
62.	Your parent's PD has an impact on the life of your **well** parent? NA					
63.	Your parent's PD has an impact on the life of your **whole family**?					

SECTION B: Please answer YES or No to these questions.

Information for you

		YES	NO
64.	Do you have all the information you need about PD?		
65.	Do you feel you know enough about what will happen in the future to your parent with PD?		
66.	Do you rely solely on your parent(s) for information about PD? If no please write below from where else you receive information.		

Support for you

		YES	NO
67.	Do you feel that there is somebody you can talk to about PD if you want to?		
68.	Do you feel you have all the support you require from friends and family?		
69.	Do you have ways to deal with any anger / anxiety you may feel?		
70.	Does your parent with PD talk to you about the illness?		
71.	Would it help to have contact with people in a similar situation (e.g. through the Parkinson's Disease Society)?		

External help for you

		YES	NO
72.	Would it help you to have training in how to care for your parent with PD?		
73.	Do you think it would be helpful if you had the opportunity to have individual counselling?		
74.	Do you think it would help you to have counselling as a family?		

External help for your parents

		YES	NO
75.	Is external help available in caring for your parent with PD?		
76.	Do you think more help (e.g. meals on wheels, physiotherapy) should be provided to help care for your parent with PD?		
77.	Do you feel it would help **you** if you were able to talk to local services about any help provided for your parent with PD or your well parent?		

Instructions: *This questionnaire is divided into a number of different sections. Please **answer every question** by placing a tick in the box that describes most closely how you feel. If you are not sure about an answer please give the **best answer you can**. Certain questions might not apply to you. If this is the case please tick the* NA *box provided. This would be the case if, for example, when answering question 21, you have no brothers or sisters.*

SECTION A

About your health

		Poor	Fair	Good	Very Good	Excell -ent
1.	Would you say that, in general, your physical health is:					
2.	Thinking about your feelings, would you say that in general you feel:					
3.	And would you rate your sleep as:					

How you feel inside

	How often does your parent's PD make you feel:	All the time	Often	Some-times	Rarely	Never
4.	Sad?					
5.	Angry?					
6.	Nervous?					
7.	Neglected because of lack of attention?					

School, social life & friends

	How often:	All the time	Often	Some-times	Rarely	Never
8.	Do you feel that your parent's PD affects the quality of your schoolwork?					
9.	Do you feel that your parent's PD means you spend less time with your friends?					
10.	Do you feel that your parent's PD harms your relationships with friends?					
11.	Do you feel that your parent's PD means you spend less time on social activities, *for example* hobbies or sports?					
12.	Do you have difficulty explaining PD to your friends? NA					
13.	Do you find it difficult to deal with your friends' lack of understanding of PD? NA					
14.	Do you feel embarrassed talking to friends about PD?					
15.	Are you bullied or made fun of because of your parent's PD?					

Independence and responsibility

	How often do you feel:	All the time	Often	Some-times	Rarely	Never
16.	Your parent's PD means you have less independence?					
17.	That any increase in responsibility due to your parent's PD is a problem? NA					
18.	That your parent with PD depends on you because of their illness?					

At home

	How often do you:	All the time	Often	Some-times	Rarely	Never
19.	Do household chores (*for example* cooking, cleaning, shopping) on a regular basis?					
20.	Feel you do more household chores because one of your parents has PD?					
21.	Feel you give more help than any brothers and sisters you may have? NA					

You & your parent(s)

	How often do you feel:	All the time	Often	Some-times	Rarely	Never
22.	Your parent with PD has difficulty doing activities with you?					
23.	Your parent with PD has difficulty talking to you?					
24.	That you and your parent with PD understand each other?					
25.	Any problems you may have had with your parent with PD are due to their illness rather than anything else? NA					
26.	That your parent's PD has brought you closer together?					
27.	That any religious beliefs you hold have helped you to cope with your parents PD? NA					
28.	That you have to help / care for your parent with PD?					
29.	You understand the feelings of your parent with PD less than the feelings of your other parent? NA					
30.	That any problems you have talking with your parent with PD make you feel less close to them?					
31.	Resentful about any changes in your parent's behaviour as a result of PD, such as being impatient?					
32.	Embarrassed by the effects of PD on your parent?					

Changes in yourself

	How often do you feel:	Never	Rarely	Some-times	Often	All the time
33.	More mature as a result of your parents PD?					
34.	More understanding and sympathetic of other peoples' illness and disability as a result of your parent's PD?					
35.	That you cope better with difficult problems as a result of your parent's PD?					
36.	That as a result of your parent's PD you are better at finding ways to deal with problems?					

Your future

	To what extent:	Ext-remely	Very much	Fairly	Not much	Not at all
37.	Are you concerned that your parent's PD will affect your independence in the future?					
38.	Do you feel your parent's PD will affect when you make a decision to leave home?					
39.	Do you feel uncertain about the future because of your parent's PD?					
40.	Do you feel that your own future may be different than it otherwise might have been because of your parent's PD?					

Impact of PD on you and your family

	To what extent do you feel that:	Ext-remely	Very much	Fairly	Not much	Not at all
41.	Your parent's PD affects your own daily routine?					
42.	Your parent's PD affects the life of your whole family?					
43.	Living in the family home is more difficult now than before your parent with PD became unwell?	NA				
44.	Having a parent with PD affects your family financially?					

SECTION B: Please answer YES or No to these questions.

Information for you

		YES	NO
45.	Do you have all the information you need about PD?		
46.	Do you feel you know enough about what will happen in the future to your parent with PD?		
47.	Do you rely just on your parent(s) for information about PD? If no please write below from where else you receive information.		

Support for you

		YES	NO
48.	Do you feel that there is somebody you can talk to about PD if you want to?		
49.	Do you feel you have all the support you need from friends and family?		
50.	Do you have ways to deal with any anger / anxiety you may feel?		
51.	Does your parent with PD talk to you about the illness?		
52.	Would it help to have contact with people in a similar situation (*for example* through the Parkinson's Disease Society)?		

		YES	NO
53.	Would it help you to have training in how to care for your parent with PD?		
54.	Do you think it would be helpful if you had the opportunity to have individual counselling?		
55.	Do you think it would help you to have counselling as a family?		

Support for your parents

		YES	NO
56.	Is outside help available in caring for your parent with PD?		
57.	Do you think more help (*for example* meals on wheels, physiotherapy) should be provided to help care for your parent with PD?		
58.	Do you feel it would help <u>you</u> if you were able to talk to local services about any help provided for your parent with PD or your other parent?		

SECTION C: *Finally, please mark on the scale below how you would rate* ***your overall quality of life.*** *If you think that your quality of life is really good you should mark near the right end of the scale. If, on the other hand, you think things are really bad, you should mark near the left end of the scale.*

Instructions: *This questionnaire is divided into a number of different sections. Please **answer every question** by placing a tick in the box that describes most closely how you feel. If you are not sure about an answer please give the **best answer you can**. Certain questions might not apply to you. If this is the case please tick the* NA *box provided. This would be the case if, for example, when answering question 21, you have no brothers or sisters.*

SECTION A

About your health

		Poor	Fair	Good	Very Good	Excell-ent
1.	Would you say that, in general, your physical health is:					
2.	Would you say that, in general, emotionally you feel:					
3.	And would you rate your sleep as:					

How you feel inside

How often does your parent's PD make you feel:

		All the time	Often	Some-times	Rarely	Never
4.	Sad?					
5.	Angry?					
6.	Nervous?					
7.	Neglected because of lack of attention?					

School, social life & friends

How often:

		All the time	Often	Some-times	Rarely	Never
8.	Do you feel that your parent's PD affects the quality of your work or usual activities? NA					
9.	Do you feel that your parent's PD means you spend less time with friends?					
10.	Do you feel that your parent's PD affects your relationships with friends?					
11.	Do you feel that your parent's PD means you spend less time on social activities, *for example* hobbies or sports?					
12.	Do you have difficulty explaining PD to your friends? NA					
13.	Do you find it difficult to deal with your friends' lack of understanding of PD? NA					
14.	Do you feel embarrassed talking to friends about PD?					
15.	Are you bullied or taunted because of your parent's PD?					

Independence and responsibility

How often do you feel:	All the time	Often	Some-times	Rarely	Never
16. Your parent's PD means you have less independence?					
17. That any increase in responsibility due to your parent's PD is a burden? NA					
18. That your parent with PD depends on you because of their illness?					

At home

How often do you:	All the time	Often	Some-times	Rarely	Never
19. Get involved in the daily running of your parents' home (i.e. cooking, cleaning, shopping) on a regular basis?					
20. Feel you do more household chores because one of your parents has PD?					
21. Feel you give more help than other family members you may have? NA					

You & your parent(s)

How often do you feel:	All the time	Often	Some-times	Rarely	Never
22. Your parent with PD has difficulty doing activities with you?					
23. Your parent with PD has difficulty talking to you?					
24. That you and your parent with PD understand each other?					
25. Any problems you may have had with your parent with PD are due to their illness rather than anything else? NA					
26. That your parent's PD has brought you closer together?					
27. That any religious beliefs you hold have helped you to cope with your parents PD? NA					
28. That you have to help / care for your parent with PD?					
29. You understand the feelings of your parent with PD less than the feelings of your other parent? NA					
30. That any problems you have talking with your parent with PD make you feel less close to them?					
31. Resentful about any changes in your parent's behaviour as a result of PD, such as impatience?					
32. Embarrassed by the effects of PD on your parent?					

Changes in yourself

How often do you feel:	Never	Rarely	Some-times	Often	All the time
33. More mature as a result of your parents PD?					
34. More understanding and sympathetic of other peoples' illness and disability as a result of your parent's PD?					
35. That you cope better with difficult problems as a result of your parent's PD?					
36. That as a result of your parent's PD you are better at finding ways to deal with problems?					

Your future

To what extent:	Ext-remely	Very much	Fairly	Not much	Not at all
37. Are you concerned that your parent's PD will affect your independence in the future?					
38. Do you feel your parent's PD will influence when you make a decision to leave home? NA					
39. Do you feel uncertain about the future because of your parent's PD?					
40. Do you feel that your own future may be different than it otherwise might have been because of your parent's PD?					

Impact of PD on you and your family

To what extent do you feel that:	Ext-remely	Very much	Fairly	Not much	Not at all
41. Your parent's PD affects your own daily routine?					
42. Your parent's PD affects the life of your whole family?					
43. Living in the family home is more difficult now than before your parent with PD became unwell? NA					
44. Having a parent with PD affects your family financially?					

SECTION B: *Please answer* YES *or* No *to these questions.*

Information for you

	YES	NO
45. Do you have all the information you need about PD?		
46. Do you feel you know enough about what will happen in the future to your parent with PD?		
47. Do you rely just on your parent(s) for information about PD? If no please write below from where else you receive information.		

Support for you

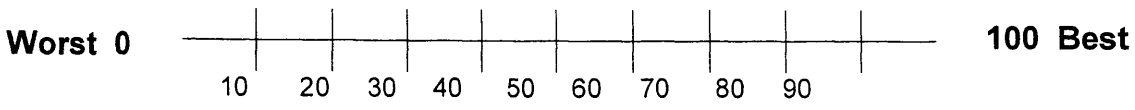
		YES	NO
48.	Do you feel that there is somebody you can talk to about PD if you want to?		
49.	Do you feel you have all the support you require from friends and family?		
50.	Do you have ways to deal with any anger / anxiety you may feel?		
51.	Does your parent with PD talk to you about the illness?		
52.	Would it help to have contact with people in a similar situation (*for example* through the Parkinson's Disease Society)?		

		YES	NO
53.	Would it help you to have training in how to care for your parent with PD?		
54.	Do you think it would be helpful if you had the opportunity to have individual counselling?		
55.	Do you think it would help you to have counselling as a family?		

Support for your parents

		YES	NO
56.	Is outside help available in caring for your parent with PD?		
57.	Do you think more help (*for example* meals on wheels, physiotherapy) should be provided to help care for your parent with PD?		
58.	Do you feel it would help <u>you</u> if you were able to talk to local services about any help provided for your parent with PD or your other parent?		

***SECTION C**: Finally, please mark on the scale below how you would rate **your overall quality of life**. If you think that your quality of life is really good you should mark near the right end of the scale. If, on the other hand, you think things are really bad, you should mark near the left end of the scale.*



Instructions: *This questionnaire is divided into a number of different sections. Please **answer every question** by placing a tick in the box that describes most closely how you feel. If you are not sure about an answer please give the **best answer you can**. Certain questions might not apply to you. If this is the case please tick the* NA *box provided. This would be the case if, for example, when answering question 21, you have no brothers or sisters.*

SECTION A

About your health

		Poor	Fair	Good	Very Good	Excell -ent
1.	Would you say that, **in the last 2 weeks**, your physical health has been:					
2.	Thinking about your feelings, would you say that, **in the last 2 weeks**, you have felt:					
3.	And, **in the last two weeks**, would you rate your sleep as:					

How you feel inside

	During the last two weeks how often has your parent's PD made you feel:	All the time	Often	Some-times	Rarely	Never
4.	Sad?					
5.	Angry?					
6.	Worried?					
7.	Neglected because of lack of attention?					

School, social life & friends

	During the last two weeks how often have you:	All the time	Often	Some-times	Rarely	Never
8.	Felt that your parent's PD affects the quality of your schoolwork?					
9.	Felt that your parent's PD means you spend less time with your friends?					
10.	Felt that your parent's PD harms your relationships with friends?					
11.	Felt that your parent's PD means you spend less time on social activities, *for example* hobbies or sports?					
12.	Had any difficulty explaining PD to your friends? NA					
13.	Found it difficult to cope with your friends' lack of understanding of PD? NA					
14.	Felt embarrassed talking to friends about PD?					
15.	Been bullied or made fun of because of your parent's PD?					

Independence and responsibility

	During the last two weeks how often have you felt that:	All the time	Often	Some-times	Rarely	Never
16.	Your parent's PD means you have less independence (*for example* going out less)?					
17.	Any increase in responsibility due to your parent's PD is a problem (*for example* looking after other family members)? NA					
18.	Your parent with PD depends on you because of their illness?					

At home

	During the last two weeks how often have you:	All the time	Often	Some-times	Rarely	Never
19.	Done household chores (*for example* cooking, cleaning, shopping) on a regular basis?					
20.	Felt you do more household chores because one of your parents has PD?					
21.	Felt you give more help than any brothers and sisters you may have? NA					

You & your parent(s)

	During the last two weeks how often have you felt:	All the time	Often	Some-times	Rarely	Never
22.	Your parent with PD has difficulty doing activities with you?					
23.	Your parent with PD has difficulty talking to you about their feelings?					
24.	That you and your parent with PD understand each other?					
25.	That any problems you may have had with your parent with PD are due to their illness (rather than anything else)? NA					
26.	That you have to help in caring for your parent with PD?					
27.	Annoyed about any changes in your parent's behaviour as a result of PD?					
28.	Embarrassed by the effects of PD on your parent?					

	How often do you feel:	All the time	Often	Some-times	Rarely	Never
29.	That your parent's PD has brought you closer together? NA					
30.	That any religious beliefs you hold have helped you to cope with your parents PD? NA					
31.	You understand the feelings of your parent with PD less than those of your other parent? NA					

Changes in yourself

	During the last two weeks how often have you felt:	Never	Rarely	Some-times	Often	All the time
32.	More understanding of other peoples' illness and disability as a result of your parent's PD?					
33.	That you coped well with difficult problems? NA					

Impact of PD on you and your family

	In the past 2 weeks to what extent have you felt that:	Ext-remely	Very much	Fairly	Not much	Not at all
34.	Your parent's PD has affected your own daily routine?					
35.	Your parent's PD has affected the life of your whole family?					
36.	Living in the family home is more difficult than before your parent with PD became unwell? NA					
37.	Having a parent with PD affects your family financially (e.g. not having enough money)?					

Your future

	To what extent:	Ext-remely	Very much	Fairly	Not much	Not at all
38.	Are you concerned that your parent's PD will affect your independence in the future?					
39.	Do you feel your parent's PD will affect when you make a decision to leave home? NA					
40.	Do you feel uncertain about the future because of your parent's PD?					
41.	Do you feel that your own future might be different (because of your parent's PD)?					
42.	Are you concerned that you might develop PD in the future?					

SECTION B: Please answer YES or NO to these questions.

Information for you

		YES	NO
43.	Do you have all the information you need about PD?		
44.	Do you feel you know enough about what will happen in the future to your parent with PD?		
45.	Do you rely just on your parent(s) for information about PD? If no please write below from where else you receive information.		

Support for you

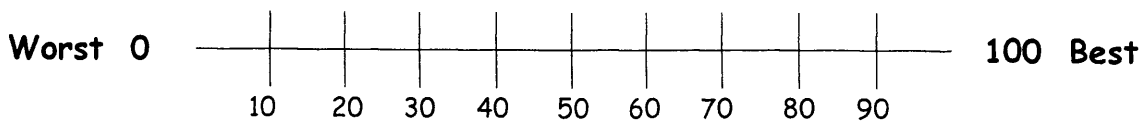
		YES	NO
46.	Do you feel that there is somebody you can talk to about PD if you want to?		
47.	Do you feel you have all the support you need from friends and family?		
48.	Do you have ways to cope with any anger you may feel?	NA	
49.	Does your parent with PD talk to you about their illness?		
50.	Would it help <u>you</u> to have contact with people in a similar situation (*for example* through the Parkinson's Disease Society)?		

		YES	NO
51.	Would it help you to have training in how to care for your parent with PD?		
52.	Do you think it would be helpful if you had the opportunity to speak to someone professionally (*for example* a counsellor)?		
53.	Do you think it would help you to have counselling as a family?		

Support for your parents

		YES	NO
54.	Is help available in caring for your parent with PD (*for example* a professional carer)?		
55.	Do you think more help (*for example* meals on wheels, physiotherapy) should be provided to help care for your parent with PD?		
56.	Do you feel it would help <u>you</u> if you were able to talk to local services about any help provided (*for example* social services)?		

***SECTION C**: Finally, please mark on the scale below how you would rate **your overall quality of life**. If you think that your quality of life is really good you should mark near the right end of the scale. If, on the other hand, you think things are really bad, you should mark near the left end of the scale.*



Instructions: *This questionnaire is divided into a number of different sections. Please **answer every question** by placing a tick in the box that describes most closely how you feel. If you are not sure about an answer please give the **best answer you can**. Certain questions might not apply to you. If this is the case please tick the* NA *box provided. This would be the case if, for example, when answering question 21, you have no brothers or sisters.*

SECTION A

About your health

		Poor	Fair	Good	Very Good	Excell-ent
1.	Would you say that, **in the last 2 weeks**, your physical health has been:					
2.	Thinking about your feelings, would you say that, **in the last 2 weeks**, you have felt:					
3.	And, **in the last two weeks**, would you rate your sleep as:					

How you feel inside

	During the last two weeks how often has your parent's PD made you feel:	All the time	Often	Some-times	Rarely	Never
4.	Sad?					
5.	Angry?					
6.	Anxious?					
7.	Neglected because of lack of attention?					

School, social life & friends

	During the last two weeks how often have you:	All the time	Often	Some-times	Rarely	Never
8.	Felt that your parent's PD affects the quality of your work or usual activities?					
9.	Felt that your parent's PD means you spend less time with your friends?					
10.	Felt that your parent's PD harms your relationships with friends?					
11.	Felt that your parent's PD means you spend less time on social activities, *for example* hobbies or sports?					
12.	Had any difficulty explaining PD to your friends? NA					
13.	Found it difficult to cope with your friends' lack of understanding of PD? NA					
14.	Felt embarrassed talking to friends about PD?					
15.	Been bullied or taunted because of your parent's PD?					

Independence and responsibility

	During the last two weeks how often have you felt that:	All the time	Often	Some-times	Rarely	Never
16.	Your parent's PD means you have less independence, *for example* going out less?					
17.	Any increase in responsibility, due to your parent's PD is a problem (*for example* looking after other family members)? NA					
18.	Your parent with PD depends on you because of their illness?					

At home

	During the last two weeks how often have you:	All the time	Often	Some-times	Rarely	Never
19.	Got involved in the daily running of your parents' home (i.e. cooking, cleaning, shopping) on a regular basis?					
20.	Felt you do more household chores because one of your parents has PD?					
21.	Felt you give more help than any brothers and sisters you may have? NA					

You & your parent(s)

	During the last two weeks how often have you felt:	All the time	Often	Some-times	Rarely	Never
22.	Your parent with PD has difficulty doing activities with you?					
23.	Your parent with PD has difficulty talking to you about their feelings?					
24.	That you and your parent with PD understand each other?					
25.	That any problems you may have had with your parent with PD are due to their illness (rather than anything else)? NA					
26.	That you have to help in caring for your parent with PD?					
27.	Annoyed about any changes in your parent's behaviour as a result of PD?					
28.	Embarrassed by the effects of PD on your parent?					

	How often do you feel:	All the time	Often	Some-times	Rarely	Never
29.	That your parent's PD has brought you closer together? NA					
30.	That any religious beliefs you hold have helped you to cope with your parents PD? NA					
31.	You understand the feelings of your parent with PD less than those of your other parent? NA					

Changes in yourself

	During the last two weeks how often have you felt:	Never	Rarely	Some-times	Often	All the time
32.	More understanding of other peoples' illness and disability as a result of your parent's PD?					
33.	That you coped well with difficult problems? NA					

Impact of PD on you and your family

	In the past 2 weeks to what extent have you felt that:	Ext-remely	Very much	Fairly	Not much	Not at all
34.	Your parent's PD has affected your own daily routine?					
35.	Your parent's PD has affected the life of your whole family?					
36.	Living in the family home is more difficult than before your parent with PD became unwell? NA					
37.	Having a parent with PD affects your family financially.					

Your future

	To what extent:	Ext-remely	Very much	Fairly	Not much	Not at all
38.	Are you concerned that your parent's PD will affect your independence in the future?					
39.	Do you feel your parent's PD will affect when you make a decision to leave home? NA					
40.	Do you feel uncertain about the future because of your parent's PD?					
41.	Do you feel that your own future might be different (because of your parent's PD)?					
42.	Are you concerned that you might develop PD in the future?					

***SECTION B**: Please answer* **YES** *or* **NO** *to these questions.*

Information for you

		YES	NO
43.	Do you have all the information you need about PD?		
44.	Do you feel you know enough about what will happen in the future to your parent with PD?		
45.	Do you rely just on your parent(s) for information about PD? If no please write below from where else you receive information.		

Support for you

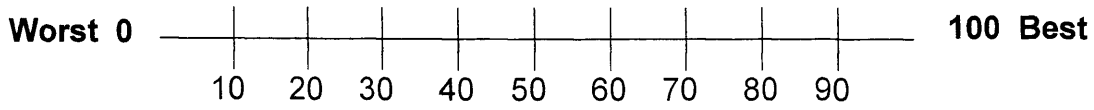
		YES	NO
46.	Do you feel that there is somebody you can talk to about PD if you want to?		
47.	Do you feel you have all the support you need from friends and family?		
48.	Do you have ways to cope with any anger you may feel? NA		
49.	Does your parent with PD talk to you about their illness?		
50.	Would it help <u>you</u> to have contact with people in a similar situation (*for example* through the Parkinson's Disease Society)?		

		YES	NO
51.	Would it help you to have training in how to care for your parent with PD?		
52.	Do you think it would be helpful if you had the opportunity to speak to someone professionally (*for example* a counsellor)?		
53.	Do you think it would help you to have counselling as a family?		

Support for your parents

		YES	NO
54.	Is help available in caring for your parent with PD (*for example* a professional carer)?		
55.	Do you think more help (*for example* meals on wheels, physiotherapy) should be provided to help care for your parent with PD?		
56.	Do you feel it would help <u>you</u> if you were able to talk to local services about any help provided (*for example* social services)?		

***SECTION C**: Finally, please mark on the scale below how you would rate **your overall quality of life**. If you think that your quality of life is really good you should mark near the right end of the scale. If, on the other hand, you think things are really bad, you should mark near the left end of the scale.*



Instructions: *This questionnaire asks about your health and well-being, and how you feel your parent's Parkinson's affects you. Your individual answers will not be shared with anyone. The questions are divided into a number of different sections. Please* ***answer every question*** *by placing a tick in the box that describes most closely how you feel. If you are not sure about an answer please give the* ***best answer you can.*** *Please note that some questions refer to the last 2 weeks, whilst others are more general. This is made clear at the beginning of each sub-section.*

SECTION A

About your health

		Poor	Fair	Good	Very Good	Excell -ent
1.	Would you say that, **in the last 2 weeks**, your physical health has been:					
2.	Thinking about your feelings, would you say that, **in the last 2 weeks**, you have felt:					
3.	And, **in the last two weeks**, would you rate your sleep as:					

How you feel inside

	During the last two weeks how often has your parent's PD made you feel:	All the time	Often	Some-times	Rarely	Never
4.	Sad?					
5.	Angry?					
6.	Worried?					
7.	That your schoolwork is affected?					

Your social life

	During the last two weeks how often have you felt that:	All the time	Often	Some-times	Rarely	Never
8.	Your parent's PD means you spend less time with your friends?					
9.	Your parent's PD harms your relationships with friends?					
10.	Your parent's PD means you spend less time on social activities, *for example* hobbies or sports?					
11.	Your parent's PD means you have less independence (*for example* going out less)?					
12.	Your parent's PD has affected your own daily routine?					
13.	Having a parent with PD affects your family financially (*for example* not having enough money)?					

You and your parent with PD

	How often do you feel:	All the time	Often	Some-times	Rarely	Never
14.	That you and your parent with PD understand each other?					
15.	That your parent's PD has brought you closer together?					
16.	Embarrassed by the effects of PD on your parent?					

At home

	During the last two weeks how often have you:	All the time	Often	Some-times	Rarely	Never or not appli-cable
17.	Done household chores (*for example* cooking, cleaning, shopping) on a regular basis?					
18.	Felt you do more household chores because one of your parents has PD?					
19.	Felt you give more help than any brothers and sisters you may have?					
20.	Felt that your parent with PD depends on you because of their illness?					
21.	Felt that you have to help in caring for your parent with PD?					
22.	Felt that any increase in responsibility due to your parent's PD is a problem (*for example* looking after other family members)?					
23.	Felt that living in the family home is more difficult than before your parent with PD became unwell?					
24.	Felt that your parent's PD will affect when you make a decision to leave home?					

Communication & understanding

	During the last two weeks how often have you felt:	All the time	Often	Some-times	Rarely	Never or not appli-cable
25.	That your parent with PD has difficulty talking to you about their feelings?					
26.	That you understand the feelings of your parent with PD less than those of your other parent?					
27.	That any problems you may have had with your parent with PD are due to their illness (rather than anything else)?					
28.	That your parent with PD has difficulty doing activities with you?					
29.	That your parent's PD has affected the life of your whole family?					
30.	Annoyed about any changes in your parent's behaviour as a result of PD?					
31.	More understanding of other peoples' illness and disability as a result of your parent's PD?					

Your friends

	During the last two weeks how often have you:	All the time	Often	Some-times	Rarely	Never or not appli-cable
32.	Had any difficulty explaining PD to your friends?					
33.	Found it difficult to cope with your friends' lack of understanding of PD?					
34.	Felt embarrassed talking to friends about PD?					

Your future

	To what extent:	Ext-remely	Very much	Fairly	Not much	Not at all
35.	Are you concerned that your parent's PD will affect your independence in the future?					
36.	Do you feel uncertain about the future because of your parent's PD?					
37.	Do you feel that your own future might be different (because of your parent's PD)?					

SECTION B: Please answer YES or NO to these questions.

Information for you

		YES	NO
38.	Do you have all the information you need about PD?		
39.	Do you feel you know enough about what will happen in the future to your parent with PD?		
40.	Do you rely just on your parent(s) for information about PD? If no please write below from where else you receive information.		

Support for you

		YES	NO
41.	Do you feel that there is somebody you can talk to about PD if you want to?		
42.	Do you feel you have all the support you need from friends and family?		
43.	Do you have ways to cope with any anger you may feel?		
44.	Does your parent with PD talk to you about their illness?		

		YES	NO
45.	Would it help <u>you</u> to have contact with people in a similar situation (*for example* through the Parkinson's Disease Society)?		
46.	Would it help you to have training in how to care for your parent with PD?		
47.	Do you think it would be helpful if you had the opportunity to speak to someone professionally (*for example* a counsellor)?		
48.	Do you think it would help you to have counselling as a family?		

Support for your parents

		YES	NO
49.	Is help available in caring for your parent with PD (*for example* a professional carer)?		
50.	Do you think more help (*for example* meals on wheels, physiotherapy) should be provided to help care for your parent with PD?		
51.	Do you feel it would help <u>you</u> if you were able to talk to local services about any help provided (*for example* social services)?		

SECTION C: *Finally, please mark on the scale below how you would rate* ***your overall quality of life.*** *If you think that your quality of life is really good you should mark near the right hand end of the scale. If, on the other hand, you think things are really bad, you should mark near the left hand end of the scale.*

Instructions: *This questionnaire asks about your health and well-being, and how you feel your parent's Parkinson's affects you. Your individual answers will not be shared with anyone. The questions are divided into a number of different sections. Please* ***answer every question*** *by placing a tick in the box that describes most closely how you feel. If you are not sure about an answer please give the* ***best answer you can****. Please note that some questions refer to the last 2 weeks, whilst others are more general. This is made clear at the beginning of each sub-section.*

SECTION A

About your health

		Poor	Fair	Good	Very Good	Excell-ent
1.	Would you say that, **in the last 2 weeks**, your physical health has been:					
2.	Thinking about your feelings, would you say that, **in the last 2 weeks**, you have felt:					
3.	And, **in the last two weeks**, would you rate your sleep as:					

How you feel inside

	During the last two weeks how often has your parent's PD made you feel:	All the time	Often	Some-times	Rarely	Never
4.	Sad?					
5.	Angry?					
6.	Worried?					
7.	That your work or usual activities are affected?					

Your social life

	During the last two weeks how often have you felt that:	All the time	Often	Some-times	Rarely	Never
8.	Your parent's PD means you spend less time with your friends?					
9.	Your parent's PD harms your relationships with friends?					
10.	Your parent's PD means you spend less time on social activities, *for example* hobbies or sports?					
11.	Your parent's PD means you have less independence (*for example* going out less)?					
12.	Your parent's PD has affected your own daily routine?					
13.	Having a parent with PD affects your family financially (*for example* not having enough money)?					

You and your parent with PD

	How often do you feel:	All the time	Often	Some-times	Rarely	Never
14.	That you and your parent with PD understand each other?					
15.	That your parent's PD has brought you closer together?					
16.	Embarrassed by the effects of PD on your parent?					

At home

	During the last two weeks how often have you:	All the time	Often	Some-times	Rarely	Never or not appli-cable
17.	Done household chores (*for example* cooking, cleaning, shopping) on a regular basis?					
18.	Felt you do more household chores because one of your parents has PD?					
19.	Felt you give more help than any brothers and sisters you may have?					
20.	Felt that your parent with PD depends on you because of their illness?					
21.	Felt that you have to help in caring for your parent with PD?					
22.	Felt that any increase in responsibility due to your parent's PD is a problem (*for example* looking after other family members)?					
23.	Felt that living in the family home is more difficult than before your parent with PD became unwell?					
24.	Felt that your parent's PD will affect when you make a decision to leave home?					

Communication & understanding

	During the last two weeks how often have you felt:	All the time	Often	Some-times	Rarely	Never or not appli-cable
25.	That your parent with PD has difficulty talking to you about their feelings?					
26.	That you understand the feelings of your parent with PD less than those of your other parent?					
27.	That any problems you may have had with your parent with PD are due to their illness (rather than anything else)?					
28.	That your parent with PD has difficulty doing activities with you?					
29.	That your parent's PD has affected the life of your whole family?					
30.	Annoyed about any changes in your parent's behaviour as a result of PD?					
31.	More understanding of other peoples' illness and disability as a result of your parent's PD?					

Your friends

	During the last two weeks how often have you:	All the time	Often	Some-times	Rarely	Never or not appli-cable
32.	Had any difficulty explaining PD to your friends?					
33.	Found it difficult to cope with your friends' lack of understanding of PD?					
34.	Felt embarrassed talking to friends about PD?					

Your future

	To what extent:	Ext-remely	Very much	Fairly	Not much	Not at all
35.	Are you concerned that your parent's PD will affect your independence in the future?					
36.	Do you feel uncertain about the future because of your parent's PD?					
37.	Do you feel that your own future might be different (because of your parent's PD)?					

***SECTION B**: Please answer* **YES** *or* **NO** *to these questions.*

Information for you

		YES	NO
38.	Do you have all the information you need about PD?		
39.	Do you feel you know enough about what will happen in the future to your parent with PD?		
40.	Do you rely just on your parent(s) for information about PD? If no please write below from where else you receive information.		

Support for you

		YES	NO
41.	Do you feel that there is somebody you can talk to about PD if you want to?		
42.	Do you feel you have all the support you need from friends and family?		
43.	Do you have ways to cope with any anger you may feel?		
44.	Does your parent with PD talk to you about their illness?		
45.	Would it help you to have contact with people in a similar situation (*for example* through the Parkinson's Disease Society)?		

		YES	NO
46.	Would it help you to have training in how to care for your parent with PD?		
47.	Do you think it would be helpful if you had the opportunity to speak to someone professionally (*for example* a counsellor)?		
48.	Do you think it would help you to have counselling as a family?		

Support for your parents

		YES	NO
49.	Is help available in caring for your parent with PD (*for example* a professional carer)?		
50.	Do you think more help (*for example* meals on wheels, physiotherapy) should be provided to help care for your parent with PD?		
51.	Do you feel it would help you if you were able to talk to local services about any help provided (*for example* social services)?		

***SECTION C**: Finally, please mark on the scale below how you would rate **your overall quality of life**. If you think that your quality of life is really good you should mark near the right hand end of the scale. If, on the other hand, you think things are really bad, you should mark near the left hand end of the scale.*

Higher scores indicate superior quality of life. Items are scored as follows:

		Poor	Fair	Good	Very Good	Excell-ent
		1	2	3	4	5

		All the time	Often	Some-times	Rarely	Never or not appli-cable
		1	2	3	4	5

		Ext-remely	Very much	Fairly	Not much	Not at all
		1	2	3	4	5

Items 14, 15 & 31 are **reverse-scored**.

Appendix B: Key Informant Interview Transcripts

Appendix B-i: Semi-structured interview schedule for key informant interviews

		At Diagnosis	Now	The Future
1.	How you feel inside, emotions.			
2.	Your behaviour			
3.	Your social life			
4.	The future			
5.	Home life			
6.	Relationship with unwell parent			
7.	Relationship with well parent			
8.	Performance at school / college / work			
9.	Level of information			
10.	Degree of support			
11.	Help you receive			
12.	Help your parents receive			
13.	Effects of your parents on you			
14.	Your friends			
15.	The impact of PD on your family			

Appendix B-ii: Key informant interview transcripts

Participant Number (PN) 1: 26 year old white, British female. One brother and one sister, both older. Currently in full-time employment, but living in mother's home. Does, however, live away from home during the week due to work commitments. 12 years of age at parent's diagnosis. Father deceased. University graduate (psychology).

1. Did not understand at diagnosis what Parkinson's meant, although through reading was aware it was 'something neurological'. Recalls neurological illness coming up at school and as a result of further reading became increasingly worried that mother 'would die within 10 years'. Although talked to mother who explained her condition, recalls feelings of anxiety, sadness, feeling afraid and scared for the future, and also a little anger. Did not feel neglected due to her mother's illness and maintained a 'relatively normal level of happiness'. Now feels more positive due to the relatively slow progression of PD in her mother, but does feel slightly anxious about her mother's gradual loss of independence. Mother requires regular reassurance. A 'bit' anxious for the future, although reported having 'adjusted' to the situation.
2. Does not recall any particularly bad behaviour at diagnosis or through adolescence, although did probably take advantage of mother's condition. For example, recalls using mother's worsening memory as an excuse for staying out late; 'I did tell you Mum' being a standard response. Felt that rebelled in the same way as any other child, and that the only difference with her peers was 'had a time-bomb on my shoulders'. Now feels that she is more caring than perhaps otherwise might have been. Sees her caring role as growing in the future, and probably ultimately resulting in being mother's full-time carer. This is not regarded as a burden.
3. Felt missed out slightly on social activities after diagnosis and through adolescence due to need to give mother extra help, which was resented. Also reports that this 'extra role' affected independence. Mother's PD does not affect either relationships or social activities now. Some concerns for the future in relation to social life and relationships with friends due to potential role as carer, and thereby becoming restricted.
4. At diagnosis felt uncertain for development. This general anxiety regarding personal development remains now, although there is acceptance that this will be the case in future years as mother's PD progresses.
5. Reported doing more than felt she should around the home during adolescence, particularly when compared to peers and also felt gave more help than brother and sister. Did not recall any financial impact after diagnosis, but mother did not work before diagnosis anyway.
6. Mother had difficulties talking about illness at and after diagnosis possibly due to daughter's young age. Now mother talks openly and emotionally about her condition. PN1 does not talk to her mother about her fears for the future, but feels her mother will talk more as she grows older.
7. Not applicable
8. Did not affect schoolwork after diagnosis or through adolescence. Felt guilty going away to university, but mother would not let her PD affect PN1. Does not affect work now, and tends to adopt a 'life's to short' attitude. Recognises that may have to give up work in the future in order to become full-time carer. This does not cause anxiety as this would be entirely through personal choice.
9. No information was given at diagnosis, but recalls that would have liked something such as a leaflet. Now would like to know more information, e.g. current research, and new forms of treatment.
10. Reports adequate support both at diagnosis and now, although somewhat disgruntled that mother had only recently received a disabled badge. Worried about availability of support for the future, and recognises that contact with PDS may be helpful.
11. None at present.
12. Mother still totally independent.
13. Feels that she grew-up more quickly as a result of mother's PD, through extra responsibility. Now feels slightly old before her time.

14. Reported no change in relationships or problems with friends at diagnosis and through adolescence. None were cruel or entered into bullying, although mother did only have a slight tremor. Friends often thought it was Alzheimer's, and were confused by the fact that Parkinson's was generally regarded as a illness of old-age. No problems with friends / relationships now.
15. Recognises that impact on mother is massive, but could be very much worse. Progression has been remarkably slow. Has influenced certain decisions of PN1, e.g. her not working abroad. Mother's illness has drawn whole family closer together. Mother does not like other family members talking to those outside the family unit about her PD. Does not anticipate any problems with regard to grandparent / grandchild relationships. No problems with siblings.

PN2: 13 year old white, British male. One older brother, and one younger sister. Age 11 at mother's diagnosis. Recent history of behavioural difficulties. Was hiding under dining-room table covered in boxes on arrival.

1. Didn't really know what Parkinson's meant at mother's diagnosis, and so 'didn't care'. Now feels a 'bit different', but still 'doesn't really care'. Gives a bit more help now, and is happy most of the time.
2. Behaviour changed at diagnosis because doesn't like school. Has now been suspended 6 times in 2 years. Behaviour is now improving. (Mother – problem child. Sees educational psychologist at regular intervals, instigated by her).
3. Recalls no change in social life / activities at diagnosis. Has a little less time now due to more help being required around the home. Not overly concerned about the future.
4. Not discussed
5. Gives more help around the house than feels should be the case. Has particular jobs to do which are discussed first. Feels has more responsibility than would if mother was not unwell, although does not resent this. Does not perceive any financial difficulties.
6. Did not want to talk to mother about PD at diagnosis. Now views their relationship as having 'ups and downs', and has difficulties talking with mother both in general, and about Parkinson's.
7. Gets on well with father, although again refers to 'ups and downs'.
8. Feels performance at school has worsened since mother's diagnosis.
9. States that the topic of PD is 'too medical', and that no leaflets have been made available. Does not anticipate reading about the illness in the future.
10. Could talk to mother or father for support, but doesn't want to
11. Not discussed
12. Not discussed
13. Not discussed
14. Has spoken to friends about mothers PD by 'dropping into conversation'. This has caused no problems. (Mother – friends have bullied and taunted him about her Parkinson's)
15. Sees main impact on family as him having to give more help around the home. Not sure about the effects of Parkinson's on mother and father. Does not get on well with brother and sister now, and doesn't anticipate this improving in the future.

PN3: 17 year old white, British male. One younger sister, and one younger brother. Remains in family home, and still in full-time education. Training to be a zoo-keeper. Age 14 at mother's diagnosis.

1. At diagnosis recalls asking mother if she had PD, and was not surprised when she confirmed that she had. Now feels OK about mothers Parkinson's although will probably worry more as her illness progresses.
2. Behaviour unaffected by mother's PD
3. No problems with social life / activities although feels this may be affected in the future through necessity to 'help out more'. Views own independence as unaffected.

4. At diagnosis recalls thinking that might not be able to go out as much as before, but currently has few concerns. Possible concerns for the future, although 'doesn't really think about it too much'.
5. Recalls no change at home at diagnosis, but does feel does more now around the house than peers. Regards this as greater personal responsibility, although bears no resentment. Little concern for the future as will probably have left home.
6. Wishes mother wasn't quite so independent on 'bad days'. Wants to help her but she becomes 'ratty'. Now views this as 'mustn't help too much'. No discussion between the two in relation to PD, which is not regarded as a problem.
7. Has an 'OK' relationship with father, but does not talk to him about mother's PD. Feels the two do not understand each other at times.
8. Had difficulties concentrating at school at mothers diagnosis, but this was in conjunction with the fact that grandmother had also recently died. No current problems, and has not thought about any problems for the future.
9. At diagnosis did not want any further information as too frightened due to grandfather having Parkinson's. Feels requires no further information now or in the future due to knowledge gained from grandfather.
10. Can talk to mother for support if requires, but would not talk to father as feels they are not close enough.
11. Has college counsellor, but doesn't know if would use it.
12. Not discussed
13. May well influence decision to leave home
14. Has spoken to a few friends and experienced some problems. Recalls school friends taunting with 'tell your mum she's useless at parking', but this ceased after explaining mother had PD. College friends are unaware of mother's illness, which regards as OK. Does, however, become upset if peer group taunt people who display tremor. Mother's Parkinson's has also lead to development of an altruistic nature to those who need help, although will only do so if asked.
15. Views mother as 'preparing' for progression of illness, and possible move to a bungalow. Thinks father feels guilty for going to work if mother is 'having a bad day'. Has an 'OK' relationship with siblings – 'get on as well as any brothers and sisters would'.

PN4: 29 year old white, British female. Married, living with husband, in full-time employment, and pregnant with first child. Has one older brother and one younger sister. Age 14 at mother's diagnosis. Father deceased.

1. At diagnosis had no idea what Parkinson's was, or whether mother would die or not. Did not ask mother about PD as was worried this might upset her, but did read up about it in school library. Recalls feelings of anxiety, and talking to brother and sister, which helped. Emotions now depend on how Mother has been. Real concerns a few years ago before mother's medication, but L-DOPA has caused a dramatic improvement. Now has more energy for mother and feels very sympathetic towards her needs. Although mother remains independent, feels she still need s to be encouraged to be so. Worries for when PD progresses. Fear of the unknown for the future. Feels rapid progression will come soon.
2. Recalls rebelling as 'any other teenager would'. Father had also recently passed away, so any bad behaviour was attributed to this. Rather than using mothers PD to her advantage, recalls mother using it to her own advantage. For example, told mother things, who then said she couldn't remember. Now talks of frustration at having the same conversation with mother over again due to her fading memory. Feels need to make people aware in advance of her mother's 'lateness' (poor time-keeping) prior to any arrangement.
3. Probably had a better social life after mother's diagnosis than otherwise would have! Mother very preoccupied with bringing up 3 children and having PD. Recalls having only one holiday during this period as there was 'too much else going on'. Social life is affected now due to mother asking PN4 to do things, which involves spending entire weekend with her. This is

viewed as being sent on something of a 'guilt trip'. Anticipates this continuing / accelerating in the future as mother's PD progresses.

4. Recalls thinking 'does this mean mum is going to die soon?' New mum would need care in the future, but also new that couldn't give up own life to care for her. Clearly remembers thinking would need to earn enough money in the future to employ a carer, and feeling guilty about this. Now wishes had more time to spend with mother, but could if really wanted to. Mother became dependent on PN4 at age 16 due to brother going to university. This fuelled need to become more independent through going to university and then working abroad for 3 years. Felt guilty about this at the time and still does now. Sees any future burden as being shared between the three children, something the three have discussed.
5. At diagnosis already doing a lot around the house (i.e. cooking, paperwork, cleaning), and felt did more than brother or sister, or friends did in their homes. Recalls feeling that there was enough time for TV. This increased responsibility was viewed as a burden, and something that was resented. Feelings of guilt as thought was not doing as much as should. Now there are 'odd things' that has to do for mother. Recognises that mother will need more help as PD progresses in the future, and worries about when se will require a full-time carer.
6. Relationship with mother did not change at diagnosis – 'varied from treading on eggshells to flaming rows'. Did not modify behaviour at first, but change in mother emotionally due to PD changed their relationship a couple of years later. Recalls frustration at mother not helping herself, and also 'playing the victim' with PN4, her brother and sister. Mother is less dependent on PN4 now, something that has been the case since spending time abroad, but mother's dependence has transferred to younger sister, although older brother does help 'begrudgingly'. Relationship is currently 'reaffirming itself' due to PN4 being pregnant – 'mother / daughter bonding'. Recognises will be reliant to some extent on mother after birth of child.
7. Not applicable
8. At mothers diagnosis school performance was more affected by father's death, but 2 years on poor performance at school by PN4 is attributed to mother's PD. Schoolwork suffered, could not concentrate, and became depressed (see 12). Had to resit A levels, in part due to mothers PD. Subsequently considered university 'a breeze', this being attributed to having gone away (Oxford) to redo A levels and therefore having adjusted to life away from home, and away from mother's Parkinson's. Now only affects are if mother calls at work, something she has done on 2 occasions, causing PN4 considerable distress. Anticipates no problems with regard to this in the future.
9. No information given at diagnosis, but did find information for self. Would now like to know more information about areas such as treatments for PD, and current research.
10. At diagnosis PN4 received no help at all, and now feels that this would have been helpful. Feels mother has enough support now, but only through instigating this herself. Mothers participation in 'conductive learning' programme has been excellent for her confidence, and PN4 has been surprised at mother's enthusiasm and level of participation. Again voices concerns for when mother loses independence.
11. At diagnosis PN4 feels that her school should have recognised her depression. This period in PN4's life is described as a 'bad experience', and 'coloured' the rest of her time there. Now PN4 feels no necessity for any assistance / counselling. With regard to the future PN4 has concerns about what she can do when her mother deteriorates – 'can anyone help?'
12. N/A
13. PN4 feels that Mother's PD lead to her growing up more quickly, in combination with her Father dying. Her mother felt helpless and was dependent on PN4, leading to feelings of being 'old before her time'. These feelings no longer persist.
14. Remembers not having friends in her year, but did have friends 1-2 years older. As a mature child, always had friends that were older. PN4 feels that this advanced maturity had more to do with her father's death than mother's diagnosis of PD. PN4 was open with closest friends about mum's PD, and found these friends to be 'very good'. Now is happy to talk or offer information. Mother's PD has no effect on current friendships.
15. At diagnosis mothers PD 'divided the family', and currently 'causes tension'. At time of mother's diagnosis recalls a close relationship with brother, whilst sister was still at a young

age. Got on well with brother due to attending same school, and having same friends. Remembers missing brother when he went to university at age 18 (PN4 age 16). This put 'pressure back on' PN4, who also recalls younger sister being 'a nightmare' at this stage. During the last 10 years however, has become increasingly close with sister. Although critical of each other, they maintain mutual respect. This is not so with brother, probably due to personality. PN4 becomes annoyed when brother treats mother badly, something she talks to him about. Relationships with brother and sister are regarded as well established and unlikely to change. In relation to the future PN4 suggests that her and her younger sister will talk about the impact on the family, but that her brother will not.

Other information offered: Grandchildren – sister in law is nervous about mother handling grandchild. Mother's medication has alleviated these concerns. PN4 hopes that the grandparent / grandchild relationship with her own forthcoming child will be 'normal' for as long as possible.

PN5:12 year-old, white British female. Three sisters aged 7, 8 & 14. In full time education, living in family home. Age 6 at father's diagnosis.

1. At diagnosis didn't really know about PD – shocked confused. Now father's PD makes PN5 feel a bit sad as it limits activities, and she worries when away from home. Feels things will get harder as she gets older, but is not worried about this
2. At diagnosis recalls being 'violent', aggressive and argumentative with sisters. Was also quieter at school. Now behaves a lot better, and tries to make sisters do the same. Anticipates no change in the future.
3. No changes at diagnosis and now has a good circle of friends so no problem with social activities. Anticipates no problems in the future.
4. PN5 thought the future might be affected at first, but received reassurance from her mother. Does not have concerns about the future now, and does not anticipate having any in the future.
5. Cannot remember at diagnosis, but now feels does more around the house than otherwise would have done, and more than friends. Doesn't do more than other sisters – perhaps less. Doesn't see any changes to this in the future.
6. No change in relationship with father at diagnosis. Now has no problems talking to father but doesn't really need as has enough information. Again, anticipates no change in this in the future.
7. At diagnosis got closer to mother as needed extra support. Now has 'excellent relationship' with mum and sees this as being maintained in the future.
8. No change in performance at school at diagnosis. Occasionally worries at school if Dad's had a bad day, but has no problems concentrating. Feels dad's PD may affect performance at school in the future if the PD gets worse.
9. At diagnosis had a very basic knowledge of PD, which was enough. PN5 asked more questions as she got over. Now understands PD and is happy with that level of knowledge. Might be interested in treatments and research in the future.
10. Happy with level of support at diagnosis, and now talks to friends. Anticipates no problems in the future.
11. N/A
12. No concerns in relation to this.
13. No memories when father first diagnosed, and now does not feel effected (not grown older quicker). Does not feel that father's PD will affect decision to leave home in the future.
14. No changes at diagnosis as friends were young and therefore did not understand. Now talks to friends openly, and has no anxieties in doing so. Anticipates no problems in the future.
15. At diagnosis Mum was very worried, and elder sister became very overprotective of PN5. They now have 'sisterly fights', although misses sisters when away. Feels that the family is 'normal' but that in the future the family will stay closer because of father's PD.

PN6:14 year-old white, British female. Three sisters aged 7, 8, & 12. In full-time education, living in family home. Age 8 at father's diagnosis.

1. At diagnosis didn't really understand. Just thought father had an illness that would pass – confused. Now worried, sad and resentful – 'why my dad?' However, feels independent. Worried about the future, 'scary, afraid, not sure what will happen'.
2. At diagnosis treated father differently, was upset. Now feels frustrated, but keeps this inside / away from dad. However, talks to mother and oldest of three sisters. In the future wants to help more – father 'burdened with 4 children'.
3. At diagnosis can't remember. Now father is still very active, so there are no problems with activities, and no differences with friends. In the future PN6 foresees that there will be no lifts in car due to fathers PD, and will therefore have to take the bus instead, which she does not view as a problem.
4. PN6 didn't know how her father's PD would affect the future at diagnosis as she was uncertain about his rate of decline. Now this is not a concern, although she feels that in the future leaving home might be difficult.
5. At diagnosis PN6 helped more, although this was instigated by her mother. Now she feels she helps more than her friends do, and more than she would had her father not been diagnosed with P.D. PN6 states that her mother will not currently employ a cleaner, but may do in the future.
6. At diagnosis refers to her relationship with her father changing, and being 'more wary'. Now father gets frustrated, and PN6 feels anger and frustration herself. She talks to her father about his illness and this makes it 'not so scary'. PN6 does not anticipate problems with her relationship with her father in the future.
7. At her fathers diagnosis PN6 describes her mother as less patient and 'nagging', with requests to 'help and behave'. Now she experiences no problems talking with her mother. When asked about her future relationship with her mother PN6 states that 'mum will always be there'
8. No change at diagnosis. Is upset now when father comes up to school. Occasionally has problems concentrating. Gets worried at night, although this doesn't really affect sleep. PN6 feels that her fathers PD will effect her performance, but not sure how.
9. At diagnosis had enough information, and this came solely from mother and father. Would now like to know more about research, treatments and side-effects. PN6 anticipates wanting more information as she grows older, e.g. cures.
10. Mother and father were the main support at diagnosis. Now PN6 receives good support from mother, father and friends. Views this as remaining the same in the future.
11. PN6 sees no necessity for any counselling, and views her mother and father as people to provide her with help in the future.
12. Now feels that more activities would help her father.
13. PN6 feels that she has grown up more quickly, is more serious and mature, but doesn't feel old before her time.
14. At diagnosis PN6 found her fathers PD embarrassing when with friends. Now she is sometimes embarrassed by his shortened temper, but has no problems with friends or being bullied. Does not see PD affecting relationships with friends in the future.
15. PN6 views PD as having affected her father's life considerably. She also refers to family activities being more limited. In the future PN6 feels holidays may be harder. At diagnosis became more protective of oldest sister. Younger sisters get annoyed when PN6 won't play due to homework, etc. Sees no problems in the future regards relationships with sisters.

Other information offered:

- Father gives up if people interrupt, rather than telling others to be quiet.
- PN6 doesn't want to invite friends round due to fathers limp – 'dad is different than other dads'.
- Father's temper is worse due to PD, although was slightly short-tempered prior to diagnosis.

18 year-old white, British female. One brother, aged 16. In full-time education, living in family home. Age 13 at father's diagnosis.

1. At diagnosis PN7 didn't really know about or understand PD, but was 'obviously sad and afraid for the future'. Now finds it more upsetting due to being more 'obvious. Finds it upsetting when father in pain, but does understand more about PD
2. Does not feel behaviour has changed either at diagnosis or currently, but feels resentful at how it might affect behaviour in future.
3. Diagnosis did not affect social life, but now 'may have to help around the house more – otherwise good'.
4. At diagnosis didn't know enough about PD to be concerned about the future, and has no concerns currently. Feels mother will 'take the brunt' of impact in the future.
5. Feels father's PD had no impact at home at diagnosis, but now PN7 does more around the home than otherwise would. States doesn't do more than friends, but does do more than brother.
6. At diagnosis no change in relationship with father, and was told 'what PD was'. Now doesn't talk about PD much, and states has 'typical father / daughter relationship' and that her father 'understands' her.
7. At fathers diagnosis no change in relationship with mother, and now have very close relationship. They 'talk a bit, and understand each other'. States that in the future mother will have to rely on other people, and possibly PN7, who is 'happy with that'.
8. No changes or problems at school at fathers diagnosis, but now states that father's PD is 'something else to think about, although this has had no effect on schoolwork. Does not anticipate any changes in the future.
9. Was given information initially by mother and father, and didn't want any more. States that now doesn't know much about PD, but does know where to access it. May want more information in the future.
10. At diagnosis had just mother and father for support, but now talks to close friends also. States 'there is always someone to talk to', and hopes that this continues in the future.
11. PN7 states that she knows she has the option of seeing a counsellor should she wish to do so.
12. Feels support offered to parents at diagnosis was adequate, although is 'not sure' currently. Feels confident support will be available in the future.
13. PN7 feels she is 'not old before her time', and that father's PD has not affected her health.
14. At father's diagnosis PN7 did not tell her friends and states that eventually her 'best friend did the telling', and she had no problems with friends' reactions. Is not embarrassed at all by father's PD and has not experienced any bullying.
15. Feels the greatest impact is on her mother, as father relies on her to do things. Feels that mother will have less 'free-time' in the future. States that there was no change initially in relationship with brother, but now argue about everything and cannot relate to each other. PN7 states that they are very different and that her brother is 'quite lazy'. Father's PD has affected things financially, in as much as there is less money for the future.

PN8: 16 year-old white, British male. 1 sister, aged 17. In full-time education, living in family home. Age 11 at father's diagnosis.

1. At diagnosis very upset and 'angry'. Did know what PD was even though only 11. Now feels a 'bit more relaxed' as fathers medication has helped condition. Still experiences feelings of anger although not as much as previously. Unsure about the future.
2. At diagnosis changed PN8's behaviour at school, as became angrier easier. Now has no effect. Unsure about the future.
3. At diagnosis no change. Now does more around the house, but this does not limit other activities. Anticipates no change in the future, although recognises fathers PD will 'effect Mum more'.

4. At diagnosis felt worried for the future - 'Dad wouldn't be here'. Now has only a small effect on PN8. No problems anticipated in the future.
5. At diagnosis did not help more initially, although did after the first year. Now PN8 has to do quite a lot more, but doesn't do more than sister, probably less. Does not view helping as a burden, and any help 'doesn't get in the way'. Feels that Mum 'will take the brunt' in the future.
6. At diagnosis no change in relationship with father, and this has not changed now - they remain close and understand each other. PN8 feels this will remain the same in the future.
7. At diagnosis no change, but now Mum 'gets angrier' and their 'relationship has deteriorated slightly'. PN8 is not overly worried and anticipates no problems in the future.
8. No change at diagnosis. Now has no problems - 'school is where I get away from it all'. Anticipates no problems in the future.
9. At diagnosis knew about PD 'from TV and stuff', and read fathers PD leaflet. Now PN8 says he doesn't like talking to his parents about PD as it makes him 'feel uncomfortable', and knows enough for his current needs. States may want more information in the future.
10. PN8 says 'needs someone to talk to every now and again'. No other information offered.
11. PN8 states that he 'keeps it inside and can't talk to mates - they don't understand. No other information offered.
12. At diagnosis can't recall, but now feels father receives enough help and support. Feels confident about support being offered in the future.
13. Might effect decision to leave home. States that 'in a way I feel like I've grown up more quickly'.
14. At diagnosis friends asked about it, and was bullied about a year after diagnosis, and this had some effect on him. Claims no problem now explaining to friends (note contradiction with point 12).
15. PN8 states his father's PD doesn't affect him much, but he gives help when he can, adding mother 'does a lot for his father'. At diagnosis no change in relationship with sister. Now PN8 rarely sees his sister, but they 'do get on'. Their relationship 'should get better as they get older'.

PN9: 58 year-old white, British female. Two brothers aged 56 and 59. Not in full-time education. Unsure of age at father's diagnosis. Parkinson's sufferer herself.

1. Always viewed father as very old, but father was 50 years old at birth. First became aware of PD during a holiday in Switzerland when noticed father's shaking. Later father became very remote and impatient due to slowness. Recalls wanting a younger father as she grew up and feeling ashamed of him because of his tremor. Embarrassed by father socially. Specifically remembers a party with dancing and boys, and recalls embarrassment as her father looked 'rather pathetic. Later felt guilty at being unsympathetic to her father's PD but this passed with time, although felt incredibly guilty at her own diagnosis.
2. Recalls rebelling as a child / adolescent but that there was not much parental control. Feels that did not rebel more than any normal child.
3. Liked to be out a lot. States was a very sociable child and liked to get away from her two brothers. Independence was not affected as a result of father's PD as had 'live in help'. Father was also away a lot.
4. Not affected
5. Things were evenly distributed between brothers and sisters. Recalls they had specific jobs, but this was not due to fathers PD. Had a happy childhood.
6. Had quite distant relationship with father. Felt didn't have a father as he was so remote. Were not close. Father was a devout catholic, and he came into conflict with his belief due to Parkinson's, although he was tremendously witty. Did not talk about his PD. Never resented father, but yearned for normal family.
7. Had a love hate relationship with mother. No support regards talking about PD although quite close.
8. Performance unaffected at school. Father very embarrassing at parents evening.

9. No information offered
10. No information offered
11. No information offered
12. No information offered
13. No information offered
14. Didn't talk to friends about fathers PD although friends were aware of it. Wasn't anyone to talk to.
15. Probably affected older brother most, but not quite sure how. Younger brother affected too – felt didn't have a father at all. Younger brother was at home during final year of father's life. Helped share the burden. Recalls father had very close relationship with older brother – 'my son is a genius

PN10: 36 year-old white, British male. One brother aged 34. Not in full-time education, but lives in parental home due to separation from partner. 30 years of age at father's diagnosis.

1. Recalls being abroad at time of mother's diagnosis, although it was initially thought to be a brain tumour and that mother might not have long to live. On return from overseas, and after being told of diagnosis of PD, 'felt nothing' as did not know what Parkinson's was, although was calmed by the fact that the condition was not life-threatening. Now PN10 finds in 'hard to see mum in pain'. With regard to the future PN10 feels mother's PD will affect him emotionally as the disease progresses, and states 'the future could be much harder work.
2. At diagnosis had baby with long-term partner to give mother a grandchild, which 'made mum a lot happier. Also tried to find more information about PD through books, etc. Separation from long-term partner then 'took over'. Now is more helpful than would have been, and would like to help more but is unable to 'fit this in'. Feels the future will be difficult as mother's PD progresses.
3. At time of diagnosis PN10 was experiencing a time of turmoil due to separation from long-term partner, so mother's PD had little impact, as is the case now. PN10 feels 'the future will be very difficult'.
4. PN10 states he does not think about the future too much. He states that 'things are not always as bad as he thinks they might have been'. Mothers PD may affect his independence in the future, and this he states is very much dependent on how his father copes. Would not move too far away as might be needed in the future to provide assistance to mother and father.
5. PN10 now gets involved more to stop mother doing too much, and that he will help more as her Parkinson's progresses.
6. Mother is 'not totally open and honest'. This does not worry PN10 apart from concerns about her 'doing too much'.
7. Father suffers from depression, which started when his mother died, and is now made worse by mother's P.D. Father retired due to suffering from M.E. PN10's relationship with his father has 'not changed much' other than encouraging father to help his mother more.
8. Has no impact currently, but could affect work if worried about mother, and would therefore stay at home.
9. At his mother's diagnosis PN10 read books on PD as states he 'wanted to'. Has enough information now although would like to read more but does not have the inclination.
10. PN10 has friends that he 'just mentions' his mother's PD to. In the future he feels he will need more, possibly practical, support, and does not feel confident that this support will be available.
11. No information offered.
12. At diagnosis mother had 'a terrible time', but now both parents are very involved with YAPP&RS which helps a great deal. Recalls Mum inviting YAPP&RS group to her birthday party, but PN10 did not feel comfortable around others with PD.
13. No information offered.
14. Has explained mothers PD in very basic terms to friends. Feels very embarrassed and self conscious when out with mother, or in some social situations.

15. PN10 states mother's PD has impacted on the whole family and changed his own views on life in general. Holidays with relatives have drawn the family closer together.

Other information offered: PN10's son now tells him that 'Gran's tired'. Not overly concerned about Grandson / Grandmother relationship at present.

PN11: 38 year-old white, British female. One sister aged 39. Not in full-time education, and not living in parental home. Age 23 at father's diagnosis.

1. At father's diagnosis upset but 'not overly'. Recalls father being 'very clever' in the way he told of his diagnosis - said he 'had a chronic illness and had to live with it'. Father was very 'matter of fact'. Participant lived overseas at time of diagnosis and so felt 'very far removed', and didn't understand effects. Now depends very much on how father is. Very close to father. Deep-brain stimulation operation was very traumatic, and the whole family gets 'very uptight' about father's condition sometimes. On bad days feels incredibly helpless and sad. Not optimistic about the future - 'cure won't come in Dad's lifetime'. Can't be gloomy about the future because father isn't. States it is difficult to see someone suffer, but tries to remain positive on a day to day basis. Essentially blocks out the future - 'I'm aware of it but don't dwell on it'.
2. At diagnosis fathers PD did not affect behaviour at all, although now it does affect certain things. When around father when 'off' finds it difficult to relax. Feels she is a more understanding person now, less argumentative and more compassionate. Feels things will worsen in the future as father's PD progresses.
3. Had no impact socially at father's diagnosis as not with father. Now it is difficult to know as lives so close and everything is interlinked. States lack of social life may be more of a lifestyle/ culture issue – having own business stops holidays, but would feel 'guilty' if away as 'would not be here for mum and dad'.
4. At father's diagnosis had no thoughts about the future – 'ignorance was bliss'. Now where father is concerned takes every day as it comes. Might feel different in the future but not sure how.
5. At diagnosis was abroad so immediate impact on home life. Now has taken over father's business, and is financially worse off than would have been, although feels quality of life is better. Could be earning a lot more money now (had previously worked for Foreign Office). Will affect more financially in the future due to close caring link.
6. No impact on relationship with father at diagnosis, but had always been close anyway. Now even closer 'if possible'. Might be because now lives closer or might due to PD, or both. Understand each other incredibly well. Feels relationship can't get any stronger than already is, although may lose some closeness in the future due to PD.
7. No impact on relationship with mother at diagnosis due to being away and having little knowledge of PD. Is now closer to mother than before, although clash as very much opposites. Feels relationship will become closer in the future as mother will be more reliant on participant in the future. Mother not good at talking about PD, and is quite bitter. Father is aware of the strain mother is under.
8. Had no impact at diagnosis as was living and working abroad. States that now can get distracted.
9. Recalls not wanting information at time of diagnosis. Father read books about PD on holiday and passed books on to participant 11 soon after (maybe a week). Found no information at local library. Has started to get information relatively recently via the internet, and is now very well informed about PD because of this. If wants to know something specific, usually based on father's current condition, now seeks information.
10. Would like a professional to talk to.
11. Does not feel further practical support for herself appropriate at present, and does not feel entitled to it in the future.
12. Would like parent's to have a professional to talk to. Financial assistance gives parents a 'boost'. Recognition of the impact of PD means an incredible amount to them.

13. No information offered
14. Not embarrassed by father's PD around friends, rather defensive. When not appropriate to explain fathers condition to somebody (i.e. when father there) gets frustrated at not being able to explain PD.
15. Affects family routine everyday. Can be called upon to alter plans at the drop of a hat. Husband lets participant 11 deal with father and is very understanding. Has very rocky relationship with sister – not close and don't understand each other. Sister is a manic depressive, has 2 children and is divorced. Sister is 'happily envious of participant 11 and has problems with the closeness of her relationship with both parents, but doesn't realize this has to be worked at. Sister calls when she needs something. Participant 11 doesn't worry about the closeness of the relationship now since sister's diagnosis of manic depression, although is frustrated diagnosis took so long, and the impact this had on the family.

Other information offered: 7 year old son never frightened of grandfather with PD – sad, but doesn't talk about it. Participant 11 states that it is very important for children to be involved. No problems with son after grandfather's DBS operation even though father had bolts in head – son was very compassionate.

Participant No12: 35 year-old white, British female. One sister aged 39, and one brother aged 38. Not in full-time education, and no longer living in family home. Age 30 at mother's diagnosis. Married with 2 children.

1. At diagnosis felt very upset, cried, although sister cried longer. Was sure mother was going to get best care possible, and this was best way of coping. Felt angry early on but not any longer. Now feels that 'half of Mum has died, the family is left with the other half, and bits are dying all the time'. States that her mother has lost her sense of humour and has become 'bland'. However, although she has changed mentally she remains positive and determined. In the future states that when her mother dies she will be 'relieved', although she is 'grieving now for all the bits mum is losing', i.e. mobility, sense of humour.
2. At diagnosis recalls being upset, and 'mildly depressed', as well as shocked. Recalls no change in her behaviour. Now states her behaviour has changed in a 'positive respect'. With regard to the future states she 'won't die with a penny', that she 'lives for the short-term', and is slightly more cynical.
3. At diagnosis no impact. Now also has no impact, rather participant12 ensures her family has regular holidays although has little money. Feels confident there will be little impact in the future.
4. At diagnosis was unsure about how the future would be affected as didn't known what PD was. Now doesn't think about the long-term future for her mother, but does consider her own future in relation to whether will she develop PD herself. Doesn't envisage mother's PD affecting her own independence anymore than she is happy to allow it, or able to cope with. Does not see herself as her mother's long-term carer, stating that if it came to it she would 'put mum in a home'. States mother's diagnosis actually pushed her to get a full-time job in order to maintain her independence.
5. Feels has no impact on home life at all as has decided to work rather than take on a caring role, as noted above. States financially better off now.
6. Relationship with mother has 'always been very good', and accepts mother's 'quirks', but states she is a very tolerant person anyway. Feels has now become 'guardian' to mother in some way, i.e. does the 'bits and pieces Dad can't except. Feels relationship will deteriorate in the future as 'how can you have a conversation with someone who can't talk'.
7. Has always got on very well with father, but now mother is very possessive of participant 12 so doesn't get a chance to speak with father much. This does not concern her as it feels this gives father a break. Feels relationship with father will improve in the future.
8. Mother's PD has no impact on performance at work, although on odd occasion feels emotionally drained. When mother's problems have been particularly pronounced can get

very drained and cry at work. Has a very stressful job working with children with behavioural difficulties.

9. Went on internet at mother's diagnosis, and contacted PDS to get information on PD, benefits, etc. Doesn't feel information is available to answer all the questions she has. Wants to know long-term prognosis. Is interested in research findings form this project, although feels mother should only know positive, and not negative findings.
10. Recalls talking to husband most at mother's diagnosis. States that now doesn't need too much support although support is there from if required mainly from husband. Doesn't feel will need more support in the future, and will contact PDS nurse if required.
11. No issues.
12. At diagnosis no help or information available for parents at all, although have assistance now as are members of the PDS. Feels parents will need more long-term assistance in the future as father gets older. Participant 12 is not confident that this will be available, but parents will pay if necessary as they have lots of money
13. Has always had old head on young shoulders and feels parent's PD has very little impact on her.
14. At mother's diagnosis was able to talk to friends – accepted mothers PD and 'got on with it'. Now talks to friends openly about mother's condition.
15. Feels family spends more money now than otherwise would. Had 'ups and downs' with sister at mother's diagnosis, but a better relationship with brother. Now relationship with sister has improved as she 'makes an effort'. Relationship with brother remains good, but does see him often. Brother is in denial regarding mothers PD. Feels relationship with brother and sister will be very different in the future but that they will always get on.

Other information offered:

- Variation in care in local area surprised participant 12, and feels very strongly that this should not be the case.
- Own children have made comments about mother's PD and have noticed shaking hand. One child would not touch hand. Mother's PD has been dealt with very openly. Grandparent / grandchild relationship has changed and evolved due to mobility problems associated with mother's PD

PN13: 12 year old, white British female. One brother aged 10, and one sister aged 13. In full-time education, and living in family home. Age 11 at father's diagnosis.

1. Doesn't know how she felt emotionally at fathers diagnosis, although now feels 'normal'. Unsure how will feel in the future.
2. Feels behaved normally at father's diagnosis, although might behave badly in the future.
3. Social life fine because holidays and friends are OK
4. No information offered
5. No information offered
6. Doesn't get on with father when misbehaves, but otherwise relationship is OK
7. Same as relationship with father, but might fall out with mother when older.
8. No information offered
9. Knows as much as wants to know for the moment. Might want to know more in the future.
10. No information offered
11. No information offered
12. Feels parents might need help in the future
13. No information offered
14. Doesn't talk to friends about father's PD.
15. Feels PD doesn't affect family. Doesn't get on particularly well with sister, but OK with brother. Feels will all get on better in the future.

PN14: 13 year old, white British female. One brother aged 10, and one sister aged 11. In full-time education, and living in family home. Age 12 at father's diagnosis.

1. Was 'not bothered' at fathers diagnosis, as is the case now. Doesn't know how will feel emotionally in the future.
2. Does not feel father's PD has affected her behaviour.
3. Fathers PD does not affect social life, and does not think it will in the future.
4. Has no concerns for the future relating to father's PD
5. No information offered
6. Feels relationship with father is 'alright' and does not think that this will change.
7. Have lots of arguments with mother over anything. When mother shouts participant 14 shouts back. Doesn't know how relationship will be in the future.
8. Has no problems at school
9. Knows enough about PD now. Might want to know more in the future.
10. Has someone to talk to if wants to.
11. No information offered.
12. No information offered.
13. No information offered.
14. Doesn't mind talking to friends about father's PD.
15. Doesn't feel father's PD affects family in any way. Relationship with brother and sister depends on what mood they are in. Will be better in future probably.

PN15: 35 year-old white, British female. One brother aged 38. Not in full-time education, but living in family home. Age 9 at father's diagnosis. Single

1. At diagnosis was not told of father's PD, although brother (3 years older) was told. Became aware of father's PD as a teenager. Recalls friends laughing at father, and feeling humiliated both for herself and her father. Was bullied at school, but not due to father's PD. Father did not support her over bullying. Through her 20s became very impatient and embarrassed at home, but protective and angry when in public. Now has a very close relationship with father, although father has become quite withdrawn. Will become primary carer if anything happens to mother.
2. Became very withdrawn at school, but not sure whether this due to father's PD or own personality. Annoyed and frustrated through childhood with fathers PD. Now when talks to father feels it is a 'one-way thing'. Finds it annoying that father does not act on plans or ask participant PN15 how *she* is.
3. As a teenager remembers people staring and laughing at father. Over time less people visited the house and PN15 was less inclined to invite people into the home. Now goes on holiday on her own. Due to living at home tries to keep some time to herself, but feels social life is severely affected by father's PD, and also friend she supports. How her father's PD affects her social life in the future depends on her circumstances, i.e. whether she moves out of parental home.
4. At father's diagnosis had no problems concerning the future as PD was played down and so was protected. Recalls father changing jobs. Concerns for independence came later. Now feels all depends on her mother, and PN15 feels a great deal of responsibility for the future and tries not to think too much about it.
5. Can't remember, but was expected to do a lot around the family home anyway.
6. At diagnosis viewed father as a very distant figure, but a charming and very funny man. Recalls that he didn't tell PN15 off very much, and was 'gentle but distant'. Father had quite high expectations of PN15. Now are very close, relaxed, laugh together and 'discuss certain things'. Feels that relationship in the future will 'depend on circumstances'
7. At father's diagnosis mother was 'very controlling' and PN15 felt slightly misunderstood. Now relationship is close, but different to that with father who PN15 describes as 'larger than life', and a sociable character. Has become closer to mother over the years, and now feels more appreciated due to her caring role.

8. Was bullied at school, and did not have a lot of friends, which may have been due to father. Felt 'a let-down' due to lack of academic ability. Changed schools at 16, and everything improved from there on. At this point felt very frustrated at father's inability to respond and articulate himself – felt very cold.
9. At diagnosis didn't talk to parents about anything, and didn't feel particularly supported by parents. Now feels relatively well supported by parents. Most close friends are supportive, but others are not so, and feel PN15 should leave home.
10. No information offered.
11. Feels training in moving and handling would be useful. Would like more information on PD, particularly emotional assistance.
12. Father has physiotherapy and goes to conductive education. PN15 feels that father should have more support, i.e. in relation to coming to terms with PD. Mother soon to commence as research participant in CBT trial.
13. PN15 feels father's PD has made her very considerate and helpful, and feels sure she wouldn't be living at home or as close to her parents had her father not been diagnosed. Feels resentment at still living at home, although 'own choice to an extent'. Feels emotionally blackmailed when mother says she 'doesn't know what she'd do without her.
14. No information offered.
15. Brother has distanced himself from family, although PN15, her mother and father have become closer. Father feels he cannot get involved with grandchildren. If PN15 were to have children, father's PD would not concern her. At diagnosis not very close with brother. Relationship very difficult due to abuse. Is now trying to get on due to her brother's children. Brother tries to get involved with father, but father makes it difficult.

Other information offered:

- Father feels he doesn't have a very important role in the family, feels useless, and cannot fulfil a traditional role. This frustrates PN15, who tries to mediate and encourage father to 'take a lead', but feels mother and father should do this themselves.
- PN15 has a tendency others first, and feels this might be due to growing up with PD.
- Unsure as to whether things would be different if mother had PD rather than father.
- Wants to move out of parental home

PN16: 11 year-old white, British male. One sister aged 16 and one brother aged 14. In full-time education, and living in family home. Age 10 at father's diagnosis.

1. At diagnosis was quite worried about father. Thought 'really big disease'. Was worried sad and scared. Now father is improving a bit and feeling better, participant 16 is getting to feel OK about it. Is not really worried about it anymore and the family have talked about it. Thinks will feel OK in the future – 'really feel fine about it'.
2. At father's diagnosis changed behaviour – tried to be nicer. Now 'being nicer is starting to wear off. Thinks will improve behaviour if father is stressed.
3. Has been no change in social life. Someone else now takes participant 16 to swimming. No reduction in time spent with friends. Does not feel social life will be affected in the future.
4. At diagnosis thought there would be no more playing football and tennis. Now thinks 'dad will get better one day'. Does not think father's PD will affect him in the future, things may even improve. Feels good and positive.
5. When father first diagnosed did more around the house, but this has now dropped off. Now does more than brother, but less than sister. Thinks is likely to do more around the home in the future.
6. Has always got on well with father, but get on even better now. Father was always away on business before diagnosis and is good to have him around more now. In the future thinks father will get better and will therefore be able to do more together. Relationship will get even better.
7. Has good relationship with mother, but before father's diagnosis cared less around the house and caused lots of damage. Now he is more careful, so 'mum's cool' and participant 16 is in

less trouble around the house. Is hoping mother will think he can look after himself in the future.
8. Father's PD does not affect schoolwork although very occasionally thinks about it at school.
9. Had heard about PD because of the Pope. Now has enough information through mother and father. When adult would like to work in a hospital, and possibly do medicine.
10. Feels had enough support when father first diagnosed and talks to parents about PD. Will continue to do this – parent's very open.
11. No information offered.
12. Father receives help from PDS and this that this is good and should continue. Father orders books about PD on Internet. Hopes information can help father more.
13. No information offered.
14. Doesn't talk to friends about PD too much, although has told them what it is. Doesn't feel embarrassed about father, but doesn't talk about it too much.
15. PD has changed the family a lot as father can't do very much – spills things a lot. When father was first diagnosed relationship with sister improved although still argues with brother a lot. Thinks relationship with brother and sister will get better as gets more mature.

PN17: 16 year-old white, British female. Two brothers aged 14. In full-time education, and living in family home. Age 15 at father's diagnosis.

1. Recalls shock at being told by mother of father's diagnosis. Tears, upset. Mother told participant 17 not to tell father that she knew of fathers PD as he had wanted to tell her. Now has no significant problems emotionally and doesn't think too much about it. Father is very positive and strong. Feels it would be very difficult emotionally if father deteriorated in the future, especially for mother.
2. Changed behaviour to being very nice at first, but this did not last too long. Father was depressed so tried to help by being nicer. Now things are normal and father's PD is viewed as a positive thing. Feels will be more considerate in the future and that father's condition will help them to bond.
3. Has had no impact socially at all, although has caused a slight problem with being able to get lifts to things. Does not see father's condition causing problems with social life in the future.
4. Was very concerned at first that father would be very ill so might impact on the future. Now does not see this as a problem.
5. At father's diagnosis felt must do more around the home. Now always does what asked to do around the home, although would not do of own volition. Plans to go to college / university so difficult to know about the future
6. At diagnosis relationship with father was good – no fighting. Now gives father a lot of 'abuse'. Are close but not physical. Doesn't know about relationship in the future.
7. Is 'very good friends' with mother. Do leisure activities together and get on well. Not sure about relationship in the future.
8. Fathers diagnosis came during school holidays, so had adjusted to situation by time returned to school. Has no problems at school at present, and does not foresee any in the future.
9. Knew nothing about PD initially, so relied on mother for information. Feels that now it would be good to know more.
10. Has very supportive family, teachers, and fellow students. Talks to mother and father if necessary
11. No information offered
12. No information offered
13. Parent's nag participant 17 about her weight loss
14. At father's diagnosis spoke to close friends. Friends are all very supportive. Does not feel any embarrassment, but finds some of father's symptoms, i.e. staring, are disconcerting.
15. No change in family unit. Just as close as before. Father around a lot more now due to giving up work. Brothers are unable to play football with father anymore. No change in relationship with brother and sister due to father's PD. Gets on well with both

PN18: 14 year-old white, British male. One sister age 16 and one brother aged 11. In full-time education, and living in family home. Age 13 at father's diagnosis.

1. When father diagnosed didn't know what would happen. Was sad and worried – 'sad for dad'. Now still feels the same but is 'handy' having father around. Participant 18 feels may worry as gets older.
2. Does not think behaviour has changed. In the future thinks father might not be able to do certain things, so as this gets worse may become more helpful.
3. States social life is better now as father is around more.
4. Was concerned and uncertain about the future at first. Is now concerned that father's PD might affect independence in the future as may need to help more.
5. Feels doesn't do much more around the house than before – sister does most things.
6. At diagnosis father was not around and now he is he 'hogs the computer'. Describes relationship with father as 'sort of close', but does not know how this will be in the future. PD has brought participant 18 closer to father as he sees him more.
7. Has a good relationship with mother but doesn't think about it too much.
8. Father's diagnosis might have affected schoolwork in first week, but now has no problems, although worries out of school. States it is hard to know if father's PD will affect schoolwork in the future.
9. At father's diagnosis had no idea about PD, but feels has enough information at present.
10. Feels was well supported at father's diagnosis. Talks to mother abut PD but not father. Feels awkward to father about PD – 'he has it'.
11. No information offered
12. No information offered
13. No information offered
14. Initially not comfortable about father's PD 'for a few months'. Now is happy talking with friends, and is not embarrassed by father's condition. States talking to friends about situation gets easier with time.
15. States that mother being more stressed puts strain on relationship with brother and sister. Finds younger brother annoying although get on well.

Appendix C: Expert Review Data

Appendix c-i: Expert review questionnaire

PIIS Evaluation Form

		Very much so	Moder-ately so	Unsatis-factorily	Not at all
1	In your opinion are all areas well represented?				
2	In your opinion are all questions appropriately phrased for the target age group?				
3	Do you think that the instrument is appropriately formatted (i.e. easy to read, appropriately laid out)?				

		Yes	No	If no please comment further:
4	In view of its aim, in your opinion, are all questions necessary and appropriate?			
5	Do you think that the instrument is of an appropriate length?			

We would be grateful for any other comments you would like to make about the instrument.

Item No:	Comments	Resolution
1.	I understand the desire to separate out the physical and mental components of health, but it still may be useful to ask this question in the general, overall format (e.g. as in Q1 of the SF36/SF12)	Global question or visual analogue scale may indeed be appropriate
2.	I understand the desire to separate out the physical and mental components of health, but it still may be useful to ask this question in the general, overall format (e.g. as in Q1 of the SF36/SF12) Q2 – wonder whether a child of 11 would be clear about what you mean by general feelings emotionally. Does this need unpacking a little bit for the younger end of the11-17 spectrum?	Agree – change to 'Thinking about your feelings would you say that in general you feel'
3.		
4.	Double-barreled question	Alter to 'sad' only
5.		
6.	Repetitive items, 6/7. Afraid, nervous very similar concepts. Are they both necessary?	Remove this item. Judged too similar to question 7, and later question
7.	Repetitive items, 6/7. Afraid, nervous very similar concepts. Are they both necessary?	See above
8.	Q8, Q9 are double barreled (jealous or neglected). Suggestion for Q9:.."guilty about how you feel inside?" (focus is feeling guilt, not restricted to jealousy or neglect). I always avoid 'double-barreled' questions by avoiding 'and/or' in the stem – children and adolescents may feel differently – sometimes jealous, sometimes neglected. These could be two separate items.	Alter to 'neglected' only – will check child understanding in cognitive debrief.

	Some double-barreled questions, e.g. 8 & 9. Double-barreled question Replace with '.....mixed up'	
9.	Q8, Q9 are double barreled (jealous or neglected). Suggestion for Q9:.."guilty about how you feel inside?" (focus is feeling guilt , not restricted to jealousy or neglect) Change this to 'guilty about the way you feel'. Some double-barreled questions, e.g. 8 & 9. Double-barreled question Double barreled	Remove item. Not necessary as evident from child interviews
10.	Does this item mean argue with parents or with people generally? (I think you mean generally) Q10-13 – not relevant to the person who is filling out the questionnaire.	Agree – not relevant to the respondent, and not relevant to QoL domains. Remove item.
11.	Q10-13 – not relevant to the person who is filling out the questionnaire.	Agree – not relevant to the respondent, and not relevant to QoL domains. Remove item.
12.	Does this item mean lie or cheat to parents or with people generally? (I think you mean generally) Double-barreled question Q10-13 – not relevant to the person who is filling out the questionnaire.	Agree – not relevant to the respondent, and not relevant to QoL domains. Remove item.
13.	Q10-13 – not relevant to the person who is filling out the questionnaire.	Agree – not relevant to the respondent, and not relevant to QoL domains. Remove item.
14.	Q14 & 16 – Not convinced that 11-17 age group would see these questions as essentially asking the same things if social	Agree – see item 16

	activities entails being with friends. Would it be useful to give examples of what you mean by social activities?	Underline not **bald**
15.		Underline not **bald**
16.	Q14 & 16 – Not convinced that 11-17 age group would see these questions as essentially asking the same things if social activities entails being with friends. Would it be useful to give examples of what you mean by social activities?	Agree – add examples of hobbies, sports activities
17.		
18.	I found the phrasing of this item a little confusing. I think you mean how much time is spent with friends (not including time spent at college / work. The response options for this item (and subsequent similar ones) seem odd to me. If someone were to respond 'Every day' and he or she actually did this everyday, then they could accurately respond by saying every week (i.e., ever day of the week) or every month (i.e., every day of the month). I would suggest response options to indicate daily, weekly (i.e., once a week) or monthly (i.e. once a month). Q18 comes as a bit of a surprise due to change in format of response options.	Remove this item – too similar to item 14
19.	Q19-28 I had a few problems with the value labels attached to the scale for these items. The labels are appropriate for questions that ask 'how often', but are not appropriate for questions that ask 'how much' – which is what I think these do. I may be interpreting the items incorrectly, but I would be thinking of value labels along the lines of 'a lot' to 'a little' or 'very much' to 'not at all' or something like that. Q19-Q23 – the response options set does not match the	See response below

	section item stem – "Do you feel…" requires a Yes/No or agreement response set, but you provide a frequency option set. I suggest changing the item stem to "How often do you feel:" Further, the common statement in each of the item stems can be stated once in the section stem – i.e. "As a result of your parent's PD, how often do you feel:"	Agree – change stem to 'How often do you feel that…'
20.	Q19-28 I had a few problems with the value labels attached to the scale for these items. The labels are appropriate for questions that ask 'how often', but are not appropriate for questions that ask 'how much' – which is what I think these do. I may be interpreting the items incorrectly, but I would be thinking of value labels along the lines of 'a lot' to 'a little' or 'very much' to 'not at all' or something like that. Q19-Q23 – the response options set does not match the section item stem – "Do you feel…" requires a Yes/No or agreement response set, but you provide a frequency option set. I suggest changing the item stem to "How often do you feel:" Further, the common statement in each of the item stems can be stated once in the section stem – i.e. "As a result of your parent's PD, how often do you feel:"	Agree – change stem to 'How often do you feel that…' Agree – change stem to 'How often do you feel that…'
21.	Q19-28 I had a few problems with the value labels attached to the scale for these items. The labels are appropriate for questions that ask 'how often', but are not appropriate for questions that ask 'how much' – which is what I think these do. I may be interpreting the items incorrectly, but I would be thinking of value labels along the lines of 'a lot' to 'a little' or 'very much' to 'not at all' or something like that. Q19-Q23 – the response options set does not match the section item stem – "Do you feel…" requires a Yes/No or agreement response set, but you provide a frequency option set. I suggest changing the item stem to "How often do you feel:" Further, the common statement in each of the item	Agree – change stem to 'How often do you feel that…' Agree – change stem to 'How often do you feel that…'

	stems can be stated once in the section stem – i.e. "As a result of your parent's PD, how often do you feel:"	
22.	Q19-28 I had a few problems with the value labels attached to the scale for these items. The labels are appropriate for questions that ask 'how often', but are not appropriate for questions that ask 'how much' – which is what I think these do. I may be interpreting the items incorrectly, but I would be thinking of value labels along the lines of 'a lot' to 'a little' or 'very much' to 'not at all' or something like that. Q19-Q23 – the response options set does not match the section item stem – "Do you feel..." requires a Yes/No or agreement response set, but you provide a frequency option set. I suggest changing the item stem to "How often do you feel:" Further, the common statement in each of the item stems can be stated once in the section stem – i.e. "As a result of your parent's PD, how often do you feel:"	Agree – change stem to 'How often do you feel that...' Agree – change stem to 'How often do you feel that...'
23.	Q.23 and Q.24 appear to be asking the same thing. Q23 & Q24 – seem to be substantially redundant. Is there a rationale for this?	Agree – Remove item 23, leave item 24 Agree – Remove item 23, leave item 24
24.	The response to this question could be in either direction, positive or negative. Scoring will need to allow for this. Q19-28 I had a few problems with the value labels attached to the scale for these items. The labels are appropriate for questions that ask 'how often', but are not appropriate for questions that ask 'how much' – which is what I think these do. I may be interpreting the items incorrectly, but I would be thinking of value labels along the lines of 'a lot' to 'a little' or 'very much' to 'not at all' or something like that. Q.23 and Q.24 appear to be asking the same thing.	Yes Agree – change stem to 'How often do you feel that...' Agree – Remove item 23, leave item 24

	Q23 & Q24 – seem to be substantially redundant. Is there a rationale for this? Q24-Q28 – Similar to earlier comments, the section stem suggests a Yes/No response option set. For these items you might consider an item asking to "to what extent…:" and provide 5-point response option set from "Not at all" to "Extremely". The individual items should then be revised to fit with the overall stem – e.g., for Q27 "To what extent…" "…do your parents depend on you because of their illness". And for Q28 "To what extent…" "…is their a limit to the amount of help…"	Agree – Remove item 23, leave item 24 Agree – change stem to 'How often do you feel that…'
25.	Q19-28 I had a few problems with the value labels attached to the scale for these items. The labels are appropriate for questions that ask 'how often', but are not appropriate for questions that ask 'how much' – which is what I think these do. I may be interpreting the items incorrectly, but I would be thinking of value labels along the lines of 'a lot' to 'a little' or 'very much' to 'not at all' or something like that. Q24-Q28 – Similar to earlier comments, the section stem suggests a Yes/No response option set. For these items you might consider an item asking to "to what extent…:" and provide 5-point response option set from "Not at all" to "Extremely". The individual items should then be revised to fit with the overall stem – e.g., for Q27 "To what extent…" "…do your parents depend on you because of their illness". And for Q28 "To what extent…" "…is their a limit to the amount of help…" Most items are now formulated in a negative way. For instance item 25: *'you feel you have more responsibility because of your parent's PD?'* is imbedded in negative statements, but can also be interpreted as positive.	Agree – change stem to 'How often do you feel that…' Agree – change stem to 'How often do you feel that…'

26.	.Q19-28 I had a few problems with the value labels attached to the scale for these items. The labels are appropriate for questions that ask 'how often', but are not appropriate for questions that ask 'how much' – which is what I think these do. I may be interpreting the items incorrectly, but I would be thinking of value labels along the lines of 'a lot' to 'a little' or 'very much' to 'not at all' or something like that. Q24-Q28 – Similar to earlier comments, the section stem suggests a Yes/No response option set. For these items you might consider an item asking to "to what extent...:" and provide 5-point response option set from "Not at all" to "Extremely". The individual items should then be revised to fit with the overall stem – e.g., for Q27 "To what extent..." "...do your parents depend on you because of their illness". And for Q28 "To what extent..." "...is their a limit to the amount of help..."	Agree – change stem to 'How often do you feel that...' Agree – change stem to 'How often do you feel that...'
27.	Q19-28 I had a few problems with the value labels attached to the scale for these items. The labels are appropriate for questions that ask 'how often', but are not appropriate for questions that ask 'how much' – which is what I think these do. I may be interpreting the items incorrectly, but I would be thinking of value labels along the lines of 'a lot' to 'a little' or 'very much' to 'not at all' or something like that. Q24-Q28 – Similar to earlier comments, the section stem suggests a Yes/No response option set. For these items you might consider an item asking to "to what extent...:" and provide 5-point response option set from "Not at all" to "Extremely". The individual items should then be revised to fit with the overall stem – e.g., for Q27 "To what extent..." "...do your parents depend on you because of their illness". And for Q28 "To what extent..." "...is their a limit to the amount of help..."	Agree – change stem to 'How often do you feel that...' Agree – change stem to 'How often do you feel that...'

28.	I believe this concerns the need for the affected parent to feel independent, but it could be made more explicit. Q19-28 I had a few problems with the value labels attached to the scale for these items. The labels are appropriate for questions that ask 'how often', but are not appropriate for questions that ask 'how much' – which is what I think these do. I may be interpreting the items incorrectly, but I would be thinking of value labels along the lines of 'a lot' to 'a little' or 'very much' to 'not at all' or something like that. Q24-Q28 – Similar to earlier comments, the section stem suggests a Yes/No response option set. For these items you might consider an item asking to "to what extent...:" and provide 5-point response option set from "Not at all" to "Extremely". The individual items should then be revised to fit with the overall stem – e.g., for Q27 "To what extent..." "...do your parents depend on you because of their illness". And for Q28 "To what extent..." "...is their a limit to the amount of help..."	Remove item – unclear as to what we are trying to elicit here.
29.	29-32. items on household chores very repetitive. Q29-34 – Again, the section stem does not invoke the frequency response option set. Change to section stem to "How often do you:"	See below Agree – change section stem to "How often do you:"
30.	29-32. items on household chores very repetitive Q.30 do more household chores than whom? Other members of the family / other people of the same age / friends? Q29-34 – Again, the section stem does not invoke the frequency response option set. Change to section stem to "How often do you:"	See below Agree – change section stem to "How often do you:"
31.	29-32. items on household chores very repetitive	Remove item - unnecessary

	Q29-34 – Again, the section stem does not invoke the frequency response option set. Change to section stem to "How often do you:" 'as and' not needed	
32.	29-32. items on household chores very repetitive Q29-34 – Again, the section stem does not invoke the frequency response option set. Change to section stem to "How often do you:" Q32 & 34 – are you asking the same thing? What are you trying to elicit?	Remove item - unnecessary
33.	Q29-34 – Again, the section stem does not invoke the frequency response option set. Change to section stem to "How often do you:"	Agree – change section stem to "How often do you:"
34.	Consistency: Item 34 refers to tasks, while the rest refers to chores. Q29-34 – Again, the section stem does not invoke the frequency response option set. Change to section stem to "How often do you:" Q32 & 34 – are you asking the same thing? What are you trying to elicit?	Remove item - unnecessary
35.	You want information about changes in amount of time rather than absolute time. The item stem indicates "daily household chores" – the obvious response, then, should be 'Ever day'. You might change this item to say "regular household chores". And as for Q18 above, I would change the response choices to be Daily, Once or Twice a Week, Once or Twice a Month, Rarely and	Remove item - unnecessary

	Never (or something similar).	
36.	Questions 36, 38,39, 43, 44, 47 - it is not going to be possible from these questions to separate out what are just normal teenager/parental relationship problems. Are you going to use the information from question 40 in influence your interpretation of the other questions? This is actually a double question – 'spending time with' and 'doing activities with'. Could they be separated? Q36-46 – change item stem to "How often do you feel"	Agree – we acknowledge that all adolescent children have problems with their parents. Agree – change to 'doing activities with' only Agree – change section stem to "How often do you feel:"
37.	Item 37 says (i.e. sports). Just wondered whether it should be (e.g. sports) Q36-46 – change item stem to "How often do you feel"	Remove item – will be picked up by item 36 Agree – change section stem to "How often do you feel:"
38.	Questions 36, 38,39, 43, 44, 47 - it is not going to be possible from these questions to separate out what are just normal teenager/parental relationship problems. Are you going to use the information from question 40 in influence your interpretation of the other questions? Q36-46 – change item stem to "How often do you feel" Why? Physically or emotionally? Is this not the same with all teenagers?	Agree – we acknowledge that all adolescent children have problems with their parents. Agree – change section stem to "How often do you feel:" Emotionally – no confusion with this item in interviews.
39.	Questions 36, 38,39, 43, 44, 47 - it is not going to be possible from these questions to separate out what are just normal teenager/parental relationship problems. Are you going to use the information from question 40 in influence your interpretation of the other questions? Q.39 understand each other. Does this item refer to understanding speech? Or some other emotional /	Agree – we acknowledge that all adolescent children have problems with their parents. Emotional – again, no confusion with this item in interviews.

	psychological understanding? Q36-46 – change item stem to "How often do you feel"	 Agree – change section stem to "How often do you feel:"
40.	Q36-46 – change item stem to "How often do you feel"	Agree – change section stem to "How often do you feel:"
41.	Q36-46 – change item stem to "How often do you feel"	Agree – change section stem to "How often do you:" Change to 'How often do you feel your parent's PD has brought you closer together?'
42.	Q36-46 – change item stem to "How often do you feel"	Agree – change section stem to "How often do you feel:"
43.	Questions 36, 38,39, 43, 44, 47 - it is not going to be possible from these questions to separate out what are just normal teenager/parental relationship problems. Are you going to use the information from question 40 in influence your interpretation of the other questions? This will depend on the relative relationship prior to the stroke. You need something worded in terms of change in the relationship. Q36-46 – change item stem to "How often do you feel" Change 'well parent' to 'other parent'	Agree – we acknowledge that all adolescent children have problems with their parents. Irrelevant – different point, not actually asking this. Agree – change section stem to "How often do you feel:" Agree – adopt this throughout
44.	Questions 36, 38,39, 43, 44, 47 - it is not going to be possible from these questions to separate out what are just normal teenager/parental relationship problems. Are you going to use the information from question 40 in influence your interpretation of the other questions? Q36-46 – change item stem to "How often do you feel"	Agree – we acknowledge that all adolescent children have problems with their parents. Agree – change section stem to "How often do you feel:"
45.	Q36-46 – change item stem to "How often do you feel"	Agree – change section stem to "How often do you feel:"
46.	Q36-46 – change item stem to "How often do you feel"	Agree – change section stem to "How often do you feel:"
47.	Questions 36, 38,39, 43, 44, 47 - it is not going to be possible from these questions to separate out what are just normal teenager/parental relationship problems. Are you going to use	Remove item – not subjective opinion.

	the information from question 40 in influence your interpretation of the other questions? Why does it need a special frequency response set? Why not include it in with Q36-Q46 (i.e., with new section stem. Physical, worry, financial...?	
48.	Questions 48, 49 – children may not even have told friends about the parental illness, so would not have experience of trying to explain it or deal with friends' fears Questions 48 - 52.I hope this isn't the case but a few children may be so isolated they don't consider they have friends. They may struggle with this section	Agree – insert NA box Disagree – interviews do not back this up and this is therefore unlikely.
49.	Questions 48, 49 – children may not even have told friends about the parental illness, so would not have experience of trying to explain it or deal with friends' fears Questions 48 – 52.I hope this isn't the case but a few children may be so isolated they don't consider they have friends. They may struggle with this section Q.49 this item assumes that friends have a 'fear' of the parent's illness. They may well do, but this item would be better phrased as 'lack of understanding' or something similar.	Agree – insert NA box Disagree – interviews do not back this up and this is therefore unlikely. Agree – adopt phrase 'lack of understanding'
50.	Questions 48 – 52. I hope this isn't the case but a few children may be so isolated they don't consider they have friends. They may struggle with this section	Disagree – interviews do not back this up and this is therefore unlikely.
51.	Questions 48 – 52.I hope this isn't the case but a few children may be so isolated they don't consider they have friends. They may struggle with this section	Disagree – interviews do not back this up and this is therefore unlikely.
52.	You want information about changes in amount of time rather than absolute time.	Remove Item

	Questions 48 – 52. I hope this isn't the case but a few children may be so isolated they don't consider they have friends. They may struggle with this section	Disagree – interviews do not back this up and this is therefore unlikely.
53.	Q19. 'Developed as individual' is a vague / wishy-washy phrase to me. I think I know what you mean, I'm not sure the proverbial man on the Clapham omnibus would. Similar for Q.53 'opportunities for personal development', yuck, sorry. Q53-Q57 & Q58-63 – I suggest you change the section stems to a "To what extent do you" and change the 5-response option set to "Not at All" to "Extremely". 'personal development' a bit too much for 11YOs? Should this be unpacked to have easily understood for 11-17 year-olds, particularly younger end?	Remove item – duplicated in item 24 Agree – will adopt this
54.	Q53-Q57 & Q58-63 – I suggest you change the section stems to a "To what extent do you" and change the 5-response option set to "Not at All" to "Extremely".	Agree – will adopt this
55.	Q53-Q57 & Q58-63 – I suggest you change the section stems to a "To what extent do you" and change the 5-response option set to "Not at All" to "Extremely".	Agree – will adopt this
56.	Q53-Q57 & Q58-63 – I suggest you change the section stems to a "To what extent do you" and change the 5-response option set to "Not at All" to "Extremely".	Agree – will adopt this
57.	Q53-Q57 & Q58-63 – I suggest you change the section stems to a "To what extent do you" and change the 5-response option set to "Not at All" to "Extremely".	Agree – will adopt this
58.	Q53-Q57 & Q58-63 – I suggest you change the section stems to a "To what extent do you" and change the 5-response option set to "Not at All" to "Extremely".	Agree – will adopt this
59.	Q53-Q57 & Q58-63 – I suggest you change the section stems to a "To what extent do you" and change the 5-response option set to "Not at All" to "Extremely".	Agree – will adopt this

60.	Q53-Q57 & Q58-63 – I suggest you change the section stems to a "To what extent do you" and change the 5-response option set to "Not at All" to "Extremely".	Agree – will adopt this
61.	Q.61 Impact on their daily life – I assume you mean the parents? Q53-Q57 & Q58-63 – I suggest you change the section stems to a "To what extent do you" and change the 5-response option set to "Not at All" to "Extremely".	Remove item – too far removed from QoL of respondent themselves
62.	Q53-Q57 & Q58-63 – I suggest you change the section stems to a "To what extent do you" and change the 5-response option set to "Not at All" to "Extremely".	Remove item – too far removed from QoL of respondent themselves
63.	Q53-Q57 & Q58-63 – I suggest you change the section stems to a "To what extent do you" and change the 5-response option set to "Not at All" to "Extremely".	Agree – will adopt this
64.		
65.		
66.	The space allowed after Q66 is very limited and would not be inviting for any written comments, particularly given the dexterity and handwriting of many children / adolescents. More space needed for response	Agree – will allow for more space Agree – will allow for more space
67.		
68.		
69.		
70.		
71.	Q71 & 76 – many children may not be familiar with the abbreviation 'e.g.'. I suggest you use the text version 'for example'.	Will write in full in italics
72.	Questions 72 – 77 If someone ticks that they want extra support will they be offered any ? or even advice about where to go ? It seems a shame to know people want/need support and not be able to do anything about it	Irrelevant to present study
73.	Questions 72 – 77 If someone ticks that they want extra	Irrelevant to present study

	support will they be offered any ? or even advice about where to go ? It seems a shame to know people want/need support and not be able to do anything about it	
74.	Questions 72 – 77 If someone ticks that they want extra support will they be offered any ? or even advice about where to go ? It seems a shame to know people want/need support and not be able to do anything about it	Irrelevant to present study
75.	Questions 72 – 77 If someone ticks that they want extra support will they be offered any ? or even advice about where to go ? It seems a shame to know people want/need support and not be able to do anything about it	Irrelevant to present study
76.	Questions 72 – 77 If someone ticks that they want extra support will they be offered any ? or even advice about where to go ? It seems a shame to know people want/need support and not be able to do anything about it Q71 & 76 – many children may not be familiar with the abbreviation 'e.g.'. I suggest you use the text version 'for example'.	Irrelevant to present study Will write in full in italics
77.	Questions 72 – 77 If someone ticks that they want extra support will they be offered any ? or even advice about where to go ? It seems a shame to know people want/need support and not be able to do anything about it	Irrelevant to present study

General Comments:

ONE section of life not asked about is girlfriend/boyfriend issues, especially in the 18+. It is a large part of life at that age.	*This is covered under friendship*
LAST THING to ask about - do they have a fear of inheriting the disease (whether one can or not)	*Covered in item 7? Possibly add in YES /NO information section.*
These are both thoughtfully produced questionnaires. The standard of presentation is good, and the instructions are easy to understand. Although a lot of items are included, the required method of answering means that completion can be accomplished in a very short space of time – even the young target group should find this to be so.	*This will be addressed in pilot study*
Precisely **when** the questionnaire is administered in relation to the timing of the parent's illness will be critical to the response obtained. I think this is an important to make about the use of the tool.	*Time since diagnosis will be asked for in demographics section*
Your questionnaires look very comprehensive, and I have nothing in particular to add.	
Some questions are complex	*Cognitive interviews / debrief will confirm if this is the case or not.*
Schooling?	*As above*
Too long	*Pilot study should indicate if this is the case or not.*
Nice questionnaire!	
The items that might be under-represented in both questionnaires are related to the benefits of caring. One can avoid feeling guilty by caring for your relatives. Most items are now formulated in a negative way. For instance item 26: *'you feel you have more responsibility because of your parent's PD?'* is imbedded in negative statements, but can also be interpreted as positive.	
I feel the instrument is too **one** tailed, i.e. nearly always implicating PD as a cause of problems. In fact it may well be a very positive bond in some instances / domains. I think it would be **much**	*Note change to item 41*

better to phrase questions like: "does your parent's PD help bring you closer together, or push you apart?" i.e. consider the possibility f a positive effect. For example children may visit a sick parent more often, especially if the parents were separated.	
Language – will all 11 year olds understand concepts? Language such as burden.	*'Burden' will be changed to 'problem'. Level of understanding will be confirmed by cognitive debrief*
My very first impression was that all the questions seemed to be presented and phrased as if nothing positive could be learned from an experience like that. When I went through it again I discovered some questions (19-23) that deal with it, which is fine. But still I have the feeling that the questionnaire attributes too many things to "having a parent with PD". For instance, could the behaviours described in questions 10-13 be attributed to that experience? Would some attribute bad behaviour to it? And if they do, what does it really mean?	*Items 10-13 removed. In relation to the questionnaire attributing too many things to "having a parent with PD", that is indeed the point.*
I do believe that it is a bit too long, but, once you start using it, you might be able through statistical analysis to select the best questions and be able to reduce it. But it might be too demanding.	*Agree*
I thought it was clear and well laid out, but I'm not wild about the font Comic Sans MS. I know people often use it, but I don't find it so clear as Arial or Times Roman.	*Only comment on this, and can check with pilot study*
I just wondered whether 11/12 year olds would be OK with expressions like physical health, emotional health, rarely (option box) and personal development (53). I wondered whether an example in brackets might help.	*Kinklaid analysis suggests that this OK but will be confirmed by cognitive debrief*
The instruments are generally comprehensive in covering health and health-related quality of life domains. In the adult child version, however, I noted that only one question related to finances and none directly to spirituality.	*Agree. Item to be included 'To what extent has your spirituality helped you cope?', with non-response option provided.*
The items on the adult child questionnaire are almost identical to the adolescent questionnaire. I would think many of the items are not relevant or appropriate to be asked of an adult child, e.g. 40-year old mother of 3 who has apparent with PD, particularly if the PD has developed since the child reached adulthood (e.g. Q13 Do you generally behave badly?).	*Item 13 removed*

I imagine you will group the items into domains differently from the format of presentation in the survey (e.g. the section on "impact on family" contains items that relate to financial well-being, social relationships, and proxy perceptions of another family members QoL, all different constructs. It may be useful to reconsider how the items are presently grouped. Also, internal consistency is described as satisfactory – is this for the entire survey or for separate domains? IC for a questionnaire is likely to be high, but has little meaning.	*Current grouping is based on factor analysis from preliminary instrument*
Many items lack directionality of impact (they don't ask if PD has had a positive or negative impact , just "impact"). Should this impact be clarified as explicitly positive or negative?	*This is a valid point – make questions positive or negative*
Overall I think the format, layout, presentation is good. But I also think the questionnaires are quite long and some of the questions are (perhaps unnecessarily?) complex. I'm no child expert but I find it hard to believe that children as young as 11,12,13 or even 14 could answer some of the questions meaningfully.....(but you can prove me wrong!)	*Will be confirmed by cognitive debrief*
Is it assumed for the 18+ questionnaire that the child is still living at home with the parent? Because that will affect the relevance of some of the questions in the at home and impact of family sections.	*All participants are asked whether they remain in the parental home in the demographics section*
I would be interested to know how you plan to score the measure? It may be useful to use some overall quality of life questions , possibly scored on a (1-10) visual analogue scale. E.G. 'how much does taking responsibility for your parents affect your day to day life', how much does running your parents home affect your day-to-day life, etc.	*Overall QoL question / visual analogue scale to be incorporated*
Are you going to give them the EQ-5D at the same time???	*Adult children participants yes. Adolescent participants will receive the generic Y-QoL instrument*
Overall I think the content of the instrument is very comprehensive and well represented. My comments, which I hope you find useful, are more on layout, grammar and readability.	
On the first page, the title indicates 'You & Your Parents PD' – will children know what PD is? I think it would be more appropriate to have the full name 'Parkinson's Disease' at first, with the abbreviation subsequently.	*Agree*

Section B – How is "Support for you" differentiated from "External help for you"? I would combine this section.	*Agree*
Section B – I am not sure how "External help" would be interpreted by children. Given that you have already used the term "Support" it might be less ambiguous to use it again (i.e., " Support for You" and "Support for Your Parent").	*Agree*
Needs to be more space – then maybe need to reduce number of questions.	*Agree*
Could the 'chores' section be shortened a little?	*Incorporated*
It is quite long and I don't know if an 11 Y.O. has the attention span.	*This will be confirmed by pilot study / cognitive debrief.*
Add in possibly worries about developing MS yourself.	*Possibly add in YES /NO information section.*
'External' in 'external help for you' and 'external help for your parents' not necessary; just leave at 'help'.	*Agree*
Is this designed for self-completion or interviewer administration?	*Self-completion*
Under the section on behaviour – would you not also be looking for any behaviours that would indicate withdrawal, etc, rather than purely disruptive behaviours.	*Section removed*
'Changes in yourself' – not sure how well this sits at this point of the questionnaire. It seems to make more sense to put towards the end of the questionnaire when you have asked about responsibilities. Perhaps you have done this purposely.	*Agree – move to above 'your future'.*
Do any of the questions act as internal consistency checks!	*Not relevant*
Regarding the length of the questionnaire with the younger end of the spectrum – do you think they could get questionnaire fatigue?	*This will be confirmed by pilot study / cognitive debrief.*
For both questionnaires, general comment is that I am interested in knowing how this will be used	*Items 10-13 removed*

as a QoL scale given the range of questions and dimensions. How are you relating some of the questions to QoL domains? i.e., section 10-13. How would scoring work. Will all of the information be used to calculate QoL scores?	
Response option psychology: Left is backwards in time and is also the least favorable option. Order the other way round.	*Agree – will change*
'How often does your parent's PD make you feel'. This is tricky. The best way to deal with this is not to refer to PD, but to have a control group without PD.	*Disagree*
'About your health', 'How you feel inside', 'Your behaviour', and 'Your social life': Maybe you should drop those domain names.	*Disagree*
Do not use **bald**, underline.	*Will incorporate*

Item No:	Comments	Resolution
1.	I understand the desire to separate out the physical and mental components of health, but it still may be useful to ask this question in the general, overall format (e.g. as in Q1 of the SF36/SF12)	Global question or visual analogue scale may indeed be appropriate
2.	I understand the desire to separate out the physical and mental components of health, but it still may be useful to ask this question in the general, overall format (e.g. as in Q1 of the SF36/SF12)	
3.		
4.	Double-barreled	Alter to 'sad' only
5.	Double-barreled	Alter to 'angry' only
6.	Repetitive items, 6/7. Afraid, nervous very similar concepts. Are they both necessary?	Remove this item. Judged too similar to question 7, and later question
7.	Repetitive items, 6/7. Afraid, nervous very similar concepts. Are they both necessary?	Alter to 'anxious' only
8.	Q8, Q9 are double-barreled (jealous or neglected). Suggestion for Q9:.."guilty about how you feel inside?" (focus is feeling guilt , not restricted to jealousy or neglect) I always avoid 'double-barreled' questions by avoiding 'and/or' in the stem – children and adolescents may feel differently – sometimes jealous, sometimes neglected. These could be two separate items. Replace with '.....mixed up'	Alter to 'neglected' only
9.	Q8, Q9 are double barreled (jealous or neglected). Suggestion for Q9:.."guilty about how you feel inside?" (focus is feeling guilt , not restricted to jealousy or neglect)	Remove item. Not necessary as evident from child interviews

	Change this to 'guilty about the way you feel'. Double barreled	
10.	Q10-13 – not relevant to the person who is filling out the questionnaire. Does this item mean argue with parents or with people generally? (I think you mean generally)	Agree – not relevant to the respondent, and not relevant to QoL domains. Remove item.
11.	Q10-13 – not relevant to the person who is filling out the questionnaire.	Agree – not relevant to the respondent, and not relevant to QoL domains. Remove item.
12.	Q10-13 – not relevant to the person who is filling out the questionnaire. Does this item mean lie or cheat to parents or with people generally? (I think you mean generally)	Agree – not relevant to the respondent, and not relevant to QoL domains. Remove item.
13.	Q10-13 – not relevant to the person who is filling out the questionnaire.	Agree – not relevant to the respondent, and not relevant to QoL domains. Remove item.
14.		Underline not **bald**
15.		Underline not **bald**
16.		
17.	Items 17 and 18. I wondered what happened if they don't go to either college or work? May not necessarily be at college yet	Add ' ...or your usual activities'.
18.	Items 17 and 18. I wondered what happened if they don't go to either college or work? I found the phrasing of this item a little confusing. I think you mean how much time is spent with friends (not including time spent at college / work. The response options for this item (and subsequent similar ones) seem odd to me. If someone were to respond 'Every	Remove this item – too similar to item 14

	day' and they actually did this everyday, then they could accurately respond by saying every week (i.e., ever day of the week) or every month (i.e., every day of the month). I would suggest response options to indicate daily, weekly (i.e., once a week) or monthly (i.e. once a month).	
19.	19 & 20: I wondered why they differed in the over 18 version. Seems to me that the under 18 versions were equally appropriate (and clearer) for the over 18s. Q19-28 I had a few problems with the value labels attached to the scale for these items. The labels are appropriate for questions that ask 'how often', but are not appropriate for questions, which ask 'how much' – which is what I think these do. I may be interpreting the items incorrectly, but I would be thinking of value labels along the lines of 'a lot' to 'a little' or 'very much' to 'not at all' or something like that. Q.19 'Developed as individual' is a vague / wishy-washy phrase to me. I think I know what you mean, I'm not sure the proverbial man on the Clapham omnibus would. Similar for Q.53 'opportunities for personal development', yuck, sorry. Q19-Q23 – the response options set does not match the section item stem – "Do you feel..." requires a Yes/No or agreement response set, but you provide a frequency option set. I suggest changing the item stem to "How often do you feel:" Further, the common statement in each of the item stems can be stated once in the section stem – i.e. "As a result of your parent's PD, how often do you feel:"	Agree – revert to child terminology. See response to point 4 Agree – revert to terminology on adolescent version Agree – change stem to 'How often do you feel that...'
20.	Q19-28 I had a few problems with the value labels attached to the scale for these items. The labels are appropriate for questions that ask 'how often', but are not appropriate for questions that ask 'how much' – which is what I think these do. I may be interpreting the items incorrectly, but I would be	Agree – change stem to 'How often do you feel that...'

	thinking of value labels along the lines of 'a lot' to 'a little' or 'very much' to 'not at all' or something like that. Q19-Q23 – the response options set does not match the section item stem – "Do you feel..." requires a Yes/No or agreement response set, but you provide a frequency option set. I suggest changing the item stem to "How often do you feel:" Further, the common statement in each of the item stems can be stated once in the section stem – i.e. "As a result of your parent's PD, how often do you feel:"	Agree – change stem to 'How often do you feel that...'
21.	Q19-28 I had a few problems with the value labels attached to the scale for these items. The labels are appropriate for questions that ask 'how often', but are not appropriate for questions that ask 'how much' – which is what I think these do. I may be interpreting the items incorrectly, but I would be thinking of value labels along the lines of 'a lot' to 'a little' or 'very much' to 'not at all' or something like that. Q19-Q23 – the response options set does not match the section item stem – "Do you feel..." requires a Yes/No or agreement response set, but you provide a frequency option set. I suggest changing the item stem to "How often do you feel:" Further, the common statement in each of the item stems can be stated once in the section stem – i.e. "As a result of your parent's PD, how often do you feel:"	Agree – change stem to 'How often do you feel that...' Agree – change stem to 'How often do you feel that...'
22.	Q19-28 I had a few problems with the value labels attached to the scale for these items. The labels are appropriate for questions that ask 'how often', but are not appropriate for questions that ask 'how much' – which is what I think these do. I may be interpreting the items incorrectly, but I would be thinking of value labels along the lines of 'a lot' to 'a little' or 'very much' to 'not at all' or something like that. Q19-Q23 – the response options set does not match the	Agree – change stem to 'How often do you feel that...'

	section item stem – "Do you feel..." requires a Yes/No or agreement response set, but you provide a frequency option set. I suggest changing the item stem to "How often do you feel:" Further, the common statement in each of the item stems can be stated once in the section stem – i.e. "As a result of your parent's PD, how often do you feel:"	Agree – change stem to 'How often do you feel that...'
23.	Q.23 and Q.24 appear to be asking the same thing. Q23 & Q24 – seem to be substantially redundant. Is there a rationale for this?	Agree – Remove item 23, leave item 24 Agree – Remove item 23, leave item 24
24.	The response to this question could be in either direction, positive or negative. Scoring will need to allow for this. Q19-28 I had a few problems with the value labels attached to the scale for these items. The labels are appropriate for questions that ask 'how often', but are not appropriate for questions that ask 'how much' – which is what I think these do. I may be interpreting the items incorrectly, but I would be thinking of value labels along the lines of 'a lot' to 'a little' or 'very much' to 'not at all' or something like that. Q.23 and Q.24 appear to be asking the same thing. Q23 & Q24 – seem to be substantially redundant. Is there a rationale for this? Q24-Q28 – Similar to earlier comments, the section stem suggests a Yes/No response option set. For these items you might consider an item asking to "to what extent...:" and provide 5-point response option set from "Not at all" to "Extremely". The individual items should then be revised to fit with the overall stem – e.g., for Q27 "To what extent..." "...do your parents depend on you because of their illness". And for Q28 "To what extent..." "...is their a limit to the amount of	Yes Agree – change stem to 'How often do you feel that...' Agree – Remove item 23, leave item 24 Agree – Remove item 23, leave item 24 Agree – change stem to 'How often do you feel that...'

	help..."	
25.	Q19-28 I had a few problems with the value labels attached to the scale for these items. The labels are appropriate for questions that ask 'how often', but are not appropriate for questions that ask 'how much' – which is what I think these do. I may be interpreting the items incorrectly, but I would be thinking of value labels along the lines of 'a lot' to 'a little' or 'very much' to 'not at all' or something like that. Q24-Q28 – Similar to earlier comments, the section stem suggests a Yes/No response option set. For these items you might consider an item asking to "to what extent...:" and provide 5-point response option set from "Not at all" to "Extremely". The individual items should then be revised to fit with the overall stem – e.g., for Q27 "To what extent..." "...do your parents depend on you because of their illness". And for Q28 "To what extent..." "...is their a limit to the amount of help..." Most items are now formulated in a negative way. For instance item 25: *'you feel you have more responsibility because of your parent's PD?'* is imbedded in negative statements, but can also be interpreted as positive.	Agree – change stem to 'How often do you feel that...' Agree – change stem to 'How often do you feel that...'
26.	Q19-28 I had a few problems with the value labels attached to the scale for these items. The labels are appropriate for questions that ask 'how often', but are not appropriate for questions that ask 'how much' – which is what I think these do. I may be interpreting the items incorrectly, but I would be thinking of value labels along the lines of 'a lot' to 'a little' or 'very much' to 'not at all' or something like that. Q24-Q28 – Similar to earlier comments, the section stem suggests a Yes/No response option set. For these items you might consider an item asking to "to what extent...:" and	Agree – change stem to 'How often do you feel that...' Agree – change stem to 'How often do you feel that...'

	provide 5-point response option set from "Not at all" to "Extremely". The individual items should then be revised to fit with the overall stem – e.g., for Q27 "To what extent..." "...do your parents depend on you because of their illness". And for Q28 "To what extent..." "...is their a limit to the amount of help..."	
27.	Q19-28 I had a few problems with the value labels attached to the scale for these items. The labels are appropriate for questions, which ask 'how often', but are not appropriate for questions that ask 'how much' – which is what I think these do. I may be interpreting the items incorrectly, but I would be thinking of value labels along the lines of 'a lot' to 'a little' or 'very much' to 'not at all' or something like that. Q24-Q28 – Similar to earlier comments, the section stem suggests a Yes/No response option set. For these items you might consider an item asking to "to what extent...:" and provide 5-point response option set from "Not at all" to "Extremely". The individual items should then be revised to fit with the overall stem – e.g., for Q27 "To what extent..." "...do your parents depend on you because of their illness". And for Q28 "To what extent..." "...is their a limit to the amount of help..."	Agree – change stem to 'How often do you feel that...' Agree – change stem to 'How often do you feel that...'
28.	I believe this concerns the need for the affected parent to feel independent, but it could be made more explicit. Q19-28 I had a few problems with the value labels attached to the scale for these items. The labels are appropriate for questions that ask 'how often', but are not appropriate for questions that ask 'how much' – which is what I think these do. I may be interpreting the items incorrectly, but I would be thinking of value labels along the lines of 'a lot' to 'a little' or 'very much' to 'not at all' or something like that.	Remove item – unclear as to what we are trying to elicit here.

	Q24-Q28 – Similar to earlier comments, the section stem suggests a Yes/No response option set. For these items you might consider an item asking to "to what extent…:" and provide 5-point response option set from "Not at all" to "Extremely". The individual items should then be revised to fit with the overall stem – e.g., for Q27 "To what extent…" "…do your parents depend on you because of their illness". And for Q28 "To what extent…" "…is their a limit to the amount of help…"	
29.	29-32. items on household chores very repetitive. Item 29 and 35. Why 'daily running' for over 18's and not 'household chores'? Over 18's can be pretty thick can't they? Q29-34 – Again, the section stem does not invoke the frequency response option set. Change to section stem to "How often do you:"	See below Agree – change section stem to "How often do you:"
30.	29-32. items on household chores very repetitive. Q.30 do more household chores than whom? Other members of the family / other people of the same age / friends? Q29-34 – Again, the section stem does not invoke the frequency response option set. Change to section stem to "How often do you:"	See below Agree – change section stem to "How often do you:"
31.	29-32. items on household chores very repetitive. Q29-34 – Again, the section stem does not invoke the frequency response option set. Change to section stem to "How often do you:"	Remove item - unnecessary
32.	29-32. items on household chores very repetitive.	Remove item - unnecessary

	Q29-34 – Again, the section stem does not invoke the frequency response option set. Change to section stem to "How often do you:" Q32 & 34 – are you asking the same thing? What are you trying to elicit?	
33.	Q29-34 – Again, the section stem does not invoke the frequency response option set. Change to section stem to "How often do you:"	Agree – change section stem to "How often do you:"
34.	Consistency: Item 34 refers to tasks, while the rest refers to chores. Item 34 again uses tasks. The rest uses chores. Q29-34 – Again, the section stem does not invoke the frequency response option set. Change to section stem to "How often do you:" Q32 & 34 – are you asking the same thing? What are you trying to elicit?	Remove item - unnecessary
35.	You want information about changes in amount of time rather than absolute time. Item 29 and 35. Why 'daily running' for over 18's and not 'household chores'? Over 18's can be pretty thick can't they? The item stem indicates "daily household chores" – the obvious response, then, should be 'Ever day'. You might change this item to say "regular household chores". And as for Q18 above, I would change the response choices to be Daily, Once or Twice a Week, Once or Twice a Month, Rarely and Never (or something similar).	Remove item - unnecessary
36.	Questions 36, 38,39, 43, 44, 47 - it is not going to be possible from these questions to separate out what are just	Agree – we acknowledge that all adolescent children have problems with their parents.

	normal teenager/parental relationship problems. Are you going to use the information from question 40 in influence your interpretation of the other questions? This is actually a double question – 'spending time with' and 'doing activities with'. Could they be separated? Q36-46 – change item stem to "How often do you feel" Are Q36 & 37 'physical activity' with you appropriate at age >18? Maybe consider activities in the community, or access to pubs, shops, etc., + similar comments to adolescent questionnaire.	 Agree – change to 'doing activities with' only Agree – change section stem to "How often do you feel:"
37.	Item 37 says (i.e. sports). Just wondered whether it should be (e.g. sports) Q36-46 – change item stem to "How often do you feel" Are Q36 & 37 'physical activity' with you appropriate at age >18? Maybe consider activities in the community, or access to pubs, shops, etc., + similar comments to adolescent questionnaire	Remove item – will be picked up by item 36 Agree – change section stem to "How often do you feel:"
38.	Questions 36, 38,39, 43, 44, 47 - it is not going to be possible from these questions to separate out what are just normal teenager/parental relationship problems. Are you going to use the information from question 40 in influence your interpretation of the other questions? Q36-46 – change item stem to "How often do you feel" Why? Physically or emotionally?	Agree – we acknowledge that all adolescent children have problems with their parents. Agree – change section stem to "How often do you feel:" Emotionally – no confusion with this item in interviews.
39.	Questions 36, 38,39, 43, 44, 47 - it is not going to be possible from these questions to separate out what are just normal teenager/parental relationship problems. Are you	Agree – we acknowledge that all adolescent children have problems with their parents.

	going to use the information from question 40 in influence your interpretation of the other questions? Q.39 understand each other. Does this item refer to understanding speech? Or some other emotional / psychological understanding? Q36-46 – change item stem to "How often do you feel"	 Emotional – again, no confusion with this item in interviews. Agree – change section stem to "How often do you feel:"
40.	Q36-46 – change item stem to "How often do you feel"	Agree – change section stem to "How often do you feel:"
41.	Q36-46 – change item stem to "How often do you feel"	Agree – change section stem to "How often do you feel:" Change to 'How often do you feel your parent's PD has brought you closer together?'
42.	Q36-46 – change item stem to "How often do you feel"	Agree – change section stem to "How often do you feel:"
43.	Questions 36, 38,39, 43, 44, 47 - it is not going to be possible from these questions to separate out what are just normal teenager/parental relationship problems. Are you going to use the information from question 40 in influence your interpretation of the other questions? This will depend on the relative relationship prior to the stroke. You need something worded in terms of change in the relationship. Q36-46 – change item stem to "How often do you feel"	Agree – we acknowledge that all adolescent children have problems with their parents. Irrelevant – different point, not actually asking this. Agree – change section stem to "How often do you feel:"
44.	Questions 36, 38,39, 43, 44, 47 - it is not going to be possible from these questions to separate out what are just normal teenager/parental relationship problems. Are you going to use the information from question 40 in influence your interpretation of the other questions? Q36-46 – change item stem to "How often do you feel"	Agree – we acknowledge that all adolescent children have problems with their parents. Agree – change section stem to "How often do you feel:"
45.	Q36-46 – change item stem to "How often do you feel"	Agree – change section stem to "How often do you feel:"
46.	Q36-46 – change item stem to "How often do you feel"	Agree – change section stem to "How often do you feel:"

47.	Questions 36, 38,39, 43, 44, 47 - it is not going to be possible from these questions to separate out what are just normal teenager/parental relationship problems. Are you going to use the information from question 40 in influence your interpretation of the other questions? Why does it need a special frequency response set? Why not include it in with Q36-Q46 (i.e., with new section stem.	Remove item – not subjective opinion.
48.	Questions 48, 49 – children may not even have told friends about the parental illness, so would not have experience of trying to explain it or deal with friends' fears Questions 48 - 52.I hope this isn't the case but a few children may be so isolated they don't consider they have friends. They may struggle with this section	Agree – insert NA box Disagree – interviews do not back this up and this is therefore unlikely.
49.	Questions 48, 49 – children may not even have told friends about the parental illness, so would not have experience of trying to explain it or deal with friends' fears Questions 48 – 52.I hope this isn't the case but a few children may be so isolated they don't consider they have friends. They may struggle with this section Q.49 this item assumes that friends have a 'fear' of the parent's illness. They may well do, but this item would be better phrased as 'lack of understanding' or something similar.	Agree – insert NA box Disagree – interviews do not back this up and this is therefore unlikely. Agree – we will adopt phrase 'lack of understanding'
50.	Questions 48 – 52. I hope this isn't the case but a few children may be so isolated they don't consider they have friends. They may struggle with this section	Disagree – interviews do not back this up and this is therefore unlikely.
51.	Questions 48 – 52.I hope this isn't the case but a few children may be so isolated they don't consider they have friends. They may struggle with this section	Disagree – interviews do not back this up and this is therefore unlikely.
52.	You want information about changes in amount of time rather	Remove item

	than absolute time. Questions 48 – 52. I hope this isn't the case but a few children may be so isolated they don't consider they have friends. They may struggle with this section	 Disagree – interviews do not back this up and this is therefore unlikely.
53.	Q.19 'Developed as individual' is a vague / wishy-washy phrase to me. I think I know what you mean, I'm not sure the proverbial man on the Clapham omnibus would. Similar for Q.53 'opportunities for personal development', yuck, sorry. Q53-Q57 & Q58-63 – I suggest you change the section stems to a "To what extent do you" and change the 5-response option set to "Not at All" to "Extremely".	Remove item – duplicated in item 24 Agree – will adopt this
54.	Q53-Q57 & Q58-63 – I suggest you change the section stems to a "To what extent do you" and change the 5-response option set to "Not at All" to "Extremely".	Agree – will adopt this
55.	Q53-Q57 & Q58-63 – I suggest you change the section stems to a "To what extent do you" and change the 5-response option set to "Not at All" to "Extremely".	Agree – will adopt this
56.	Q53-Q57 & Q58-63 – I suggest you change the section stems to a "To what extent do you" and change the 5-response option set to "Not at All" to "Extremely".	Agree – will adopt this
57.	Q53-Q57 & Q58-63 – I suggest you change the section stems to a "To what extent do you" and change the 5-response option set to "Not at All" to "Extremely".	Agree – will adopt this
58.	Q53-Q57 & Q58-63 – I suggest you change the section stems to a "To what extent do you" and change the 5-response option set to "Not at All" to "Extremely".	Agree – will adopt this
59.	Q53-Q57 & Q58-63 – I suggest you change the section stems to a "To what extent do you" and change the 5-response option set to "Not at All" to "Extremely".	Agree – will adopt this
60.	Q53-Q57 & Q58-63 – I suggest you change the section stems to a "To what extent do you" and change the 5-response option set to "Not at All" to "Extremely".	Agree – will adopt this

61.	Q53-Q57 & Q58-63 – I suggest you change the section stems to a "To what extent do you" and change the 5-response option set to "Not at All" to "Extremely".	Remove item – too far removed from QoL of respondent themselves
62.	Q53-Q57 & Q58-63 – I suggest you change the section stems to a "To what extent do you" and change the 5-response option set to "Not at All" to "Extremely".	Remove item – too far removed from QoL of respondent themselves
63.	Q53-Q57 & Q58-63 – I suggest you change the section stems to a "To what extent do you" and change the 5-response option set to "Not at All" to "Extremely".	Agree – will adopt this
64.		
65.		
66.	The space allowed after Q66 is very limited and would not be inviting for any written comments, particularly given the dexterity and handwriting of many children / adolescents.	Agree – will allow for more space
67.		
68.		
69.		
70.		
71.	Q71 & 76 – many children may not be familiar with the abbreviation 'e.g.'. I suggest you use the text version 'for example'. MS society	Will write in full in italics Agree
72.	Questions 72 – 77 If someone ticks that they want extra support will they be offered any ? or even advice about where to go ? It seems a shame to know people want/need support and not be able to do anything about it	Irrelevant to present study
73.	Questions 72 – 77 If someone ticks that they want extra support will they be offered any ? or even advice about where to go ? It seems a shame to know people want/need support and not be able to do anything about it	Irrelevant to present study
74.	Questions 72 – 77 If someone ticks that they want extra support will they be offered any ? or even advice about where to go ? It seems a shame to know people want/need	Irrelevant to present study

	support and not be able to do anything about it	
75.	Questions 72 – 77 If someone ticks that they want extra support will they be offered any ? or even advice about where to go ? It seems a shame to know people want/need support and not be able to do anything about it	Irrelevant to present study
76.	Questions 72 – 77 If someone ticks that they want extra support will they be offered any ? or even advice about where to go ? It seems a shame to know people want/need support and not be able to do anything about it Q71 & 76 – many children may not be familiar with the abbreviation 'e.g.'. I suggest you use the text version 'for example'.	Irrelevant to present study Will write in full in italics
77.	Questions 72 – 77 If someone ticks that they want extra support will they be offered any ? or even advice about where to go ? It seems a shame to know people want/need support and not be able to do anything about it	Irrelevant to present study

General Comments:

ONE section of life not asked about is girlfriend/ boyfriend issues, especially in the 18+. It is a large part of life at that age.	*This is covered under friendship*
LAST THING to ask about - do they have a fear of inheriting the disease (whether one can or not)	*Covered in item 7? Possibly add in YES /NO information section.*
These are both thoughtfully produced questionnaires. The standard of presentation is good, and the instructions are easy to understand. Although a lot of items are included, the required method of answering means that completion can be accomplished in a very short space of time – even the young target group should find this to be so.	*This will be addressed in pilot study*
Precisely **when** the questionnaire is administered in relation to the timing of the parent's illness will be critical to the response obtained. I think this is an important point to make about the use of the tool.	*Time since diagnosis will be asked for in demographics section*
Your questionnaires look very comprehensive, and I have nothing in particular to add.	
Quite long	*Item reduction should be possible at later stage*
Nice questionnaire!	
The items that might be under-represented in both questionnaires are related to the benefits of caring. One can avoid feeling guilty by caring for your relatives. Most items are now formulated in a negative way. For instance item 26: *'you feel you have more responsibility because of your parent's PD?'* is imbedded in negative statements, but can also be interpreted as positive.	
I feel the instrument is too **one** tailed, i.e. nearly always implicating PD as a cause of problems. In fact it may well be a very positive bond in some instances / domains. I think it would be **much** better to phrase questions like: "does your parent's PD help bring you closer together, or push you apart?" i.e. consider the possibility of a positive effect. For example children may visit a sick parent more often, especially if the parents were separated.	*Note change to item 41*

Are behavioural questions appropriate for an adult, e.g. 'generally behave badly' is not language an adult would usually use.	*Section removed*
Doesn't differentiate between family of person who has had the stroke and the adult's own family (as you are doing this with adults they may have their own families).	*Irrelevant*
My very first impression was that all the questions seemed to be presented and phrased as if nothing positive could be learned from an experience like that. When I went through it again I discovered some questions (19-23) that deal with it, which is fine. But still I have the feeling that the questionnaire attributes too many things to "having a parent with PD". For instance, could the behaviours described in questions 10-13 be attributed to that experience? Would some attribute bad behaviour to it? And if they do, what does it really mean?	*Items 10-13 removed. In relation to the questionnaire attributing too many things to "having a parent with PD", that is indeed the point.*
I do believe that it is a bit too long, but, once you start using it, you might be able through statistical analysis to select the best questions and be able to reduce it. But it might be too demanding.	*Agree*
My only query here is whether the respondent has to live with his/her parents. Some of the questions are only related with that sort of experience, some others are not. It should be the same for social life, at home, and some other questions. Maybe that is something you have to consider in the instructions or include as a question somewhere with demographics?	*Will be asked in demographics section*
This reminds me that there is nothing about the period you are asking about. For instance, questions 1-3, is it today, this week, past 14 days? For different questions you might have different periods, but it has to be stated clearly.	*Agree. Consider use of last 14 days, perhaps in initial instructions.*
I thought it was clear and well laid out, but I'm not wild about the font Comic Sans MS. I know people often use it, but I don't find it so clear as Arial or Times Roman.	*Only comment on this, and can check with pilot study*
The instruments are generally comprehensive in covering health and health-related quality of life domains. In the adult child version, however, I noted that only one question related to finances and none directly to spirituality.	*Agree. Item to be included 'To what extent has your spirituality helped you cope?', with non-response option provided.*

The items on the adult child questionnaire are almost identical to the adolescent questionnaire. I would think many of the items are not relevant or appropriate to be asked of an adult child, e.g. 40-year old mother of 3 who has apparent with PD, particularly if the PD has developed since the child reached adulthood (e.g. Q13 Do you generally behave badly?).	*Item 13 removed*
I imagine you will group the items into domains differently from the format of presentation in the survey (e.g. the section on "impact on family" contains items that relate to financial well-being, social relationships, and proxy perceptions of another family members QoL, all different constructs. It may be useful to reconsider how the items are presently grouped. Also, internal consistency is described as satisfactory – is this for the entire survey or for separate domains? IC for a questionnaire is likely to be high, but has little meaning.	*Current grouping is based on factor analysis from preliminary instrument*
Many items lack directionality of impact (they don't ask if PD has had a positive or negative impact, just "impact"). Should this impact be clarified as explicitly positive or negative?	*This is a valid point – make questions positive or negative*
Overall I think the format, layout, presentation is good. But I also think the questionnaires are quite long and some of the questions are (perhaps unnecessarily?) complex. I'm no child expert but I find it hard to believe that children as young as 11,12,13 or even 14 could answer some of the questions meaningfully.....(but you can prove me wrong!)	*Items 11, 12 & 13 are to be removed. Item 14 should not cause any difficulty*
Is it assumed for the 18+ questionnaire that the child is still living at home with the parent? Because that will affect the relevance of some of the questions in the 'at home' and 'impact of family sections'.	*All participants are asked whether they remain in the parental home in the demographics section*
I would be interested to know how you plan to score the measure? It may be useful to use some overall quality of life questions , possibly scored on a (1-10) visual analogue scale. E.G. 'how much does taking responsibility for your parents affect your day to day life', how much does running your parents home affect your day-to-day life, etc.	*Overall QoL question / visual analogue scale to be incorporated*
Are you going to give them the EQ-5D at the same time???	*Adult children participants yes*
Overall I think the content of the instrument is very comprehensive and well represented. My comments, which I hope you find useful, are more on layout, grammar and readability.	

On the first page, the title indicates 'You & Your Parents PD' – will children know what PD is? I think it would be more appropriate to have the full name 'Parkinson's Disease' at first, with the abbreviation subsequently.	*Agree*
Section B – How is "Support for you" differentiated from "External help for you"? I would combine this section.	*Agree*
Section B – I am not sure how "External help" would be interpreted by children. Given that you have already used the term "Support" it might be less ambiguous to use it again (i.e., " Support for You" and "Support for Your Parent").	*Agree*
Needs to be more space – then maybe need to reduce number of questions.	*Agree*
Is this designed for self-completion or interviewer administration?	*Self-completion*
Under the section on behaviour – would you not also be looking for any behaviours that would indicate withdrawal, etc, rather than purely disruptive behaviours.	*Section removed*
'Changes in yourself' – not sure how well this sits at this point of the questionnaire. It seems to make more sense to put towards the end of the questionnaire when you have asked about responsibilities. Perhaps you have done this purposely.	*Agree – move to above 'your future'.*
Do any of the questions act as internal consistency checks!	*Not relevant*
For both questionnaires, general comment is that I am interested in knowing how this will be used as a QoL scale given the range of questions and dimensions. How are you relating some of the questions to QoL domains? i.e., section 10-13. How would scoring work. Will all of the information be used to calculate QoL scores?	*Items 10-13 removed*
Response option psychology: Left is backwards in time and is also the least favorable option. Order the other way round.	*Agree – will change*
'How often does your parent's PD make you feel'. This is tricky. The best way to deal with this is not to refer to PD, but to have a control group without PD.	*Disagree*

'About your health', 'How you feel inside', 'Your behaviour', and 'Your social life': Maybe you should drop those domain names.	*Disagree*
Do not use **bald**, underline.	*Will incorporate*

Contributors:

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Appendix D: Cognitive Interview Data

N.B. Items where specific participant responses did not suggest a time reference was required, but one has been added are highlighted by ***

Analysis 1: Parental Illness Impact Scale Cognitive Interview Analysis, Age Group 11-17.

Subject #1 = male age 14
Subject #2 = male age 11
Subject #3 = female age 17
Subject #4 = female age 15
Subject #5 = female age 14

SECTION A

	About your health	Poor	Fair	Good	Very Good	Excell -ent	
1.	Would you say that, in general, your physical health is:						***

2.	Thinking about your feelings, would you say that in general you feel:						

Subject #4 stated they found this difficult to answer because feelings change daily. Suggests would be easier with time reference.

2 week time reference to be incorporated in item stem

3.	And would you rate your sleep as:						***

How you feel inside

	How often does your parent's PD make you feel:	All the time	Often	Some-times	Rarely	Never	
4.	Sad?						***

5.	Angry?					

***

6.	Nervous?					

Subject #3 found this question difficult to answer as parent's condition has worsened recently - requires time reference?

2 week time reference to be incorporated in item stem

Subject #4 was initially unsure as to whether this question related to them or their parent, and therefore had failed to refer the stem to the question. First instance of this.

Judged to be 'one-off' – no action taken.

Change nervous to worried

DM & CA concluded that worried more appropriate than nervous in this context.

7.	Neglected because of lack of attention?					

Subject #5 could not define 'neglected' but understood the question.

Judged to be 'one-off' – no action taken.

***

School, social life & friends

	How often:	All the time	Often	Some-times	Rarely	Never
8.	Do you feel that your parent's PD affects the quality of your schoolwork?					

***

9.	Do you feel that your parent's PD means you spend less <u>time</u> with your friends?					

Subject #1 states he actually spends more time with friends now.

Irrelevant – does not affect response

Subject #2 suggests we may require time referent here.

2 week time reference to be incorporated in item stem

***

10.	Do you feel that your parent's PD harms your relationships with friends?					

***

11.	Do you feel that your parent's PD means you spend less time on social activities, *for example* hobbies or sports?					

Subject #1 again states he actually spends more time on such activities now.

Irrelevant – does not affect response

***

12.	Do you have difficulty explaining PD to your friends?	NA				

Subject #3 specifically explained difficulties relating to symptoms rather than any emotional consequences - what sort of difficulties are we referring to?

Adjust to 'had any difficulty...'

***

13.	Do you find it difficult to deal with your friends' lack of understanding of PD?	NA				

+++

+++ DM & CS recommend changing 'deal' to 'cope' for consistency with other items.

***

14.	Do you feel embarrassed talking to friends about PD?					

***

15.	Are you bullied or made fun of because of your parent's PD?					

***

Independence and responsibility

	How often do you feel:	All the time	Often	Some-times	Rarely	Never
16.	Your parent's PD means you have less independence?					

Subject #2 clearly struggles to understand the meaning or concept of 'independence'. Requires re-phrasing or example.

Specific example to be included for clarification - *'for example* going out less'.

***

17.	That any increase in responsibility due to your parent's PD is a problem? NA					

Subject #2 appears to understand the question and state they find it easy to answer, but finds the concept of responsibility difficult to explain.

Subject #5 found this hard to answer as didn't understand at first, but did 'after a while'. Re-phrase?

Specific example to be included for clarification - *'for example* looking after other family members'.

***

18.	That your parent with PD depends on you because of their illness?					

***

At home

	How often do you:	All the time	Often	Some-times	Rarely	Never
19.	Do household chores (*for example* cooking, cleaning, shopping) on a regular basis?					

Subject #1 found this quite hard to answer as degree of help they give varies.

Judged to be 'one-off' – no action taken.

***

20.	Feel you do more household chores because one of your parents has PD?					

Subject #5 suggests underlining 'more'.

Judged to be 'one-off' – no action taken.

***

21.	Feel you give more help than any brothers and sisters you may have? NA					

***

You & your parent(s)

	How often do you do you feel:	All the time	Often	Some-times	Rarely	Never
22.	Your parent with PD has difficulty doing activities with you?					

***

23.	Your parent with PD has difficulty talking to you?					

***

24.	That you and your parent with PD understand each other?					

***

25.	Any problems you may have had with your parent with PD are due to their illness rather than anything else? NA					

Subject #4 found this question very long-winded, although did manage to repeat it back word perfect!

Subject #5 found this question quite long-winded, and could not repeat the question back.

Place 'rather than anything else' in brackets to perceptually shorten length of question.

***

26.	That your parent's PD has brought you closer together?					

Subject #4 found this difficult to answer as is unable to remember parent before developing PD.

Include non-response option.

27.	That any religious beliefs you hold have helped you to cope with your parents PD? NA					

28.	That you <u>have</u> to help / care for your parent with PD?					

Subject #4 found this difficult to understand as was not clear whether this was directed at them or the family as a whole. Underline / bold 'you' rather than 'help'?

+++

Judged to be 'one-off' – no action taken.

+++ DM & CS note question still double-barrelled – alter to 'help in caring for...'

***

29.	You understand the feelings of your parent with PD <u>less</u> than the feelings of your other parent?	NA				

Subject #2 struggles to explain the meaning of 'feelings', but appears to understand the question and state it is easy to answer.

Judged to be 'one-off' – no action taken.

Subject #5 found this question quite hard and had to read twice before answering.

Alter second half of question to "...than those of your other parent'.

30.	That any problems you have talking with your parent with PD make you feel <u>less close</u> to them?					

Subject #1 could not repeat this question back in their own words.

Subject #2 could not repeat this question back - may need to re-phrase.

Subject #5 again found this question found this question quite hard and had to read twice before answering.

Remove item – question difficult to answer, and regarded as too similar to item 26.

31.	<u>Resentful</u> about any changes in your parent's behavior as a result of PD, such as being impatient?					

Subject #2 could not respond to being asked 'what does the term **resentful** mean to you'?

Subject #4 states that 'resentful' is not a word they would normally use.

Replace 'resentful' with 'annoyed'.

Remove example as per adult version.

***

32.	<u>Embarrassed</u> by the effects of PD on your parent?					

***

Changes in yourself

	How often do you feel:	Never	Rarely	Some-times	Often	All the time
33.	More mature as a result of your parents PD?					

Subject #4 found this quite hard to answer as wouldn't know if parent didn't have PD. Also suggests that instead of 'mature' should be 'independent'. Same thing?

Remove Item – components of maturity already covered (i.e. independence, responsibility).

34.	More <u>understanding and sympathetic</u> of other peoples' illness and disability as a result of your parent's PD?					

+++

+++ DM & CS note question still double-barrelled – remove 'sympathetic'.

***

35.	That you <u>cope better</u> with difficult problems as a result of your parent's PD?					

Subject #2 struggled to find answer to this question, but did understand what was being asked.

Subject #3 also struggled to find answer to this question, but again understood what was being asked.

Subject #4 found this difficult to answer as states it is difficult to know how others cope, and how they would cope if parent didn't have PD.

Alter question to 'in the last two weeks how often have you felt you coped well with difficult problems?'

Add non-response option - may not have experienced any problems

***

36.	That as a result of your parent's PD you are better at <u>finding ways to deal with problems?</u>					

Subject #1 could not repeat this question back.

Subject #3 found this difficult to answer, and could not remember the question when asked to repeat back.

Remove item – clearly difficult to comprehend and considered too similar to item 35.

Your future

	To what extent:	Ext-remely	Very much	Fairly	Not much	Not at all
37.	Are you concerned that your parent's PD will affect <u>your independence in the future?</u>					

Subject #2 found the concept of 'independence' difficult to understand.

Judged to be 'one-off' – no action taken.

38.	Do you feel your parent's PD will affect when you make a decision to leave home?					

39.	Do you feel <u>uncertain</u> about the future because of your parent's PD?					

40.	Do you feel that your own future may be different than it otherwise might have been because of your parent's PD?					

Subject #1 could not repeat this question back in their own words. Too wordy and longwinded.

Subject #5 found this question long-winded and could not repeat the question back in their own words.

Alter question to 'to what extent do you feel your own future might be <u>different</u> (because of your parents PD)?'

Impact of PD on you and your family

	To what extent do you feel that:	Ext-remely	Very much	Fairly	Not much	Not at all
41.	Your parent's PD affects <u>your own</u> daily routine?					

***

42.	Your parent's PD affects the life of your <u>whole family?</u>					

Subject #3 stresses that at this point any impact is not negative, as parent is around much more. Need to clarify whether negative or positive affect.

Judged to be 'one-off' – no action taken.

***

43.	Living in the family home is more difficult now than before your parent with PD became unwell?	NA				

Subject #5 commented that this question appeared quite long, although easy to answer.

Judged to be 'one-off' – no action taken.

***

44.	Having a parent with PD affects your family <u>financially</u>?					

Subject #4 found this item difficult to comprehend but didn't know why.

Insert example 'e.g. not having enough money'

***

SECTION B: Please answer* YES *or* No *to these questions.

Information for you

		YES	NO
45.	Do you have all the information you need about PD?		
46.	Do you feel you know enough about what will happen in the future to your parent with PD?		
47.	Do you rely just on your parent(s) for information about PD? If no please write below from where else you receive information.		

	Support for you	YES	NO
48.	Do you feel that there is somebody you can talk to about PD if you want to?		

49.	Do you feel you have all the support you need from friends and family?		

50.	Do you have ways to deal with any anger / anxiety you may feel?		

Subject #4 found the phrase 'ways to deal' somewhat strange, and suggests replacing with 'cope'.

Replace 'deal' with 'cope' to maintain consistency of language throughout questionnaire

Subject #5 found this easy to answer but asked 'what if you don't experience any anger / anxiety?' Non-response box required?

Insert non-response option.

+++

+++ DM & CS note question still double-barrelled – remove anxiety.

51.	Does your parent with PD talk to you about the illness?		

52.	Would it help to have contact with people in a similar situation (*for example* through the Parkinson's Disease Society)?		

Subject #1 found this difficult to answer as did not initially think question was directed at them, but rather their parent. Suggests 'would it help **you** to...'

Alter question to 'would it help **you** to have contact with people in a similar situation (*for example* through the Parkinson's Disease Society)?'

53.	Would it help you to have training in how to care for your parent with PD?		

Subject #3 found this item difficult to answer as currently no care / help is required for parent.

Judged to be 'one-off' – no action taken.

54.	Do you think it would be helpful if you had the opportunity to have individual counselling?		

Subject #1 describes counselling as 'going to people in hospitals, and telling them your problems. Counsellors and shrinks are for people with big problems'.

Subject #2 does not understand the term 'counselling'.

Alter question to 'Do you think it would be helpful if you had the opportunity to speak to someone professionally (*for example* a counsellor)?'

55.	Do you think it would help you to have counselling as a family?		

	Support for your parents	YES	NO
56.	Is outside help available in caring for your parent with PD?		

Subject #1 describes 'outside help' as 'people who know about it, and if you don't know will educate you'.

Subject #3 found the terminology 'outside help' difficult to comprehend. This requires alteration.

Subject #5 found this question unclear.

Alter question to 'is help available in caring for your parent with PD (for example a professional carer)?'

57.	Do you think more help (*for example* meals on wheels, physiotherapy) should be provided to help care for your parent with PD?		

Subject #2 found this question difficult to answer although did not know why.

Judged to be 'one-off' – no action taken.

Subject #5 was unsure as to whether this refers to within the home or outside the home.

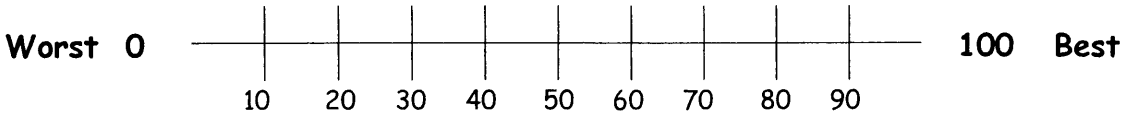
Judged to be 'one-off' – no action taken.

58.	Do you feel it would help <u>you</u> if you were able to talk to local services about any help provided for your parent with PD or your other parent?		

Subject #5 found this item 'not quite clear', and states that it is a difficult question for them at their age. Appears they feel too young to be consulted.

Alter question to 'do you feel it would help <u>you</u> if you were able to talk to local services about any help provided (*for example* social services)?'

SECTION C: *Finally, please mark on the scale below how you would rate* ***your overall quality of life****. If you think that your quality of life is really good you should mark near the right end of the scale. If, on the other hand, you think things are really bad, you should mark near the left end of the scale.*



Analysis 2

Parental Illness Impact Scale Cognitive Interview Analysis, Age Group 18+

Subject #6 = female age 31
Subject #7 = female age 39
Subject #8 = female age 36

Adjustments

SECTION A

	About your health	Poor	Fair	Good	Very Good	Excell-ent	
1.	Would you say that, in general, your physical health is:						***
2.	Would you say, that in general, emotionally you feel:						

Subject #6 found the wording and response options to this question 'strange'.

Subject #7 found the term 'in general' difficult because each day is different. Requires time referent?

} 2 week time reference to be incorporated in item stem.

3.	And would you rate your sleep as:						***

How you feel inside

	How often does your parent's PD make you feel:	All the time	Often	Some-times	Rarely	Never	
4.	Sad?						***

5.	Angry?					

***

6.	Nervous?					

Subject #6 found this question 'harder' to answer and took longer to do so. States was 'working out between response options'.

Subject #8 states that 'nervous' does 'not fit', and that nervous relates to self, whereas 'anxious' can be transferred to others. Anxious may be more appropriate.

Replace 'nervous' with 'anxious'

***

7.	Neglected because of lack of attention?					

***

School, social life & friends

How often:		All the time	Often	Some-times	Rarely	Never
8.	Do you feel that your parent's PD affects the quality of your work?	NA				

***

9.	Do you feel that your parent's PD means you spend less time with friends?					

Subject #6 hesitated and found this question difficult to answer due to no time referent.

2 week time reference to be incorporated

10.	Do you feel that your parent's PD harms your relationships with friends?					

Subject #6 suggests using 'affects' rather than 'harms'. This does not allow for distinction between positive and negative affects, and was altered to current wording after expert review.

Subject #7 suggests using 'affects' rather than 'harms'. Comment as above.

Despite the 2 comments made here DM & CS recommend overriding due to ambiguity with using 'affects'.

***

11.	Do you feel that your parent's PD means you spend less time on social activities, *for example* hobbies or sports?					

Subject #7 found this question quite hard to answer as 'needed to figure out whether reason doesn't do social activities is due to parent's PD or not'.

Judged to be 'one-off' – no action taken.

***

12.	Do you have difficulty explaining PD to your friends?	NA				

13.	Do you find it difficult to deal with your friends' lack of understanding of PD?	NA				

Subject #6 hesitated as was trying to understand what the question was asking, but appeared to have no problem answering.

No action necessary

Subject #7 read this item twice to ensure they understood the question.

No action necessary

+++

+++ DM & CS recommend changing 'deal' to 'cope' for consistency with other items.

***

14.	Do you feel embarrassed talking to friends about PD?					

***

15.	Are you bullied or taunted of because of your parent's PD?					

***

Independence and responsibility

	How often do you feel:	All the time	Often	Some-times	Rarely	Never
16.	Your parent's PD means you have less independence?					

Subject #6 commented that they were unsure how to answer as they were not more dependent on their parent, but their parent was more dependent on them

No action necessary – related to specific circumstances and perception of respondent.

Subject #8 comments that this question is harder to answer because they feel guilty when parent looks after children.

Irrelevant.

***

17.	That any increase in responsibility due to your parent's PD is a burden?	NA				

Subject #7 hesitated when answering this question as initially thought question was 'how often do you feel more responsibility?' This was removed after expert review as regarded too similar to above question with non-response option.

Judged to be 'one-off' – no action taken.

***

18.	That your parent with PD depends on you because of their illness?					

Subject #6 comments that their parent's dependence is twofold, i.e. both emotional and physical - does this require two separate questions?

Judged to be 'one-off' – no action taken.

***

At home

	How often do you:	All the time	Often	Some-times	Rarely	Never
19.	Get involved in the daily running of your parents' home (i.e. cooking, cleaning, shopping) on a regular basis?					

***

20.	Feel you do more household chores because one of your parents has PD?					

***

21.	Feel you give more help than other family members you may have?	NA				

Subject #7 made slight hesitation due to decision on response.

No action required.

***

You & your parent(s)

	How often do you feel:	All the time	Often	Some-times	Rarely	Never
22.	Your parent with PD has difficulty doing activities with you?					

***

23.	Your parent with PD has difficulty talking to you?					

Subject #6 found this question ambiguous, i.e. does this mean emotionally or physically? Requires clarification.

Subject #7 found this question difficult to answer as does not know whether referring to physically or emotionally. As above.

Subject #8 suggests clarification of this item by adding '…talking to you (about problems) or (emotions / ally)'

Change question to '…..your parent with PD has difficulty talking to you about their feelings?

***

24.	That you and your parent with PD understand each other?					

***

25.	Any problems you may have had with your parent with PD are due to their illness rather than anything else?	NA				

Subject #6 hesitated when answering this question as 'had to think about it'. Did manage to repeat question back, but with difficulty.

Subject #7 found this question slightly difficult because thing of specific instances. No problem repeating question back.

Subject #8 had to read this question twice, finding it 'hard to read and too wordy' Unable to repeat question back. Suggests removing 'rather than anything else' from the question.

Place 'rather than anything else' in brackets to perceptually shorten length of question.

***

26.	That your parent's PD has brought you closer together?					

Subject #6 took a long time to answer this question as was 'thinking about it'.

No action required

Subject #8 answers 'never' to this question as was already close to parent and PD has had not changed this. Question not working - requires adjustment.

Include non-response option.

27.	That any religious beliefs you hold have helped you to cope with your parents PD?	NA				

28.	That you have to help / care for your parent with PD?					

Subject #7 found this question '50 / 50' to answer due to emphasis on **'have'**, which means they 'needed to think about it more'

Judged to be 'one-off' – no action taken.

+++

+++ DM & CS note question still double-barrelled – alter to 'help in caring for...'

29.	You understand the feelings of your parent with PD less than the feelings of your other parent?	NA				

Subject #7 states that this question was easy to answer but 'wordy'

Alter second half of question to "...than those of your other parent'.

***

30.	That any problems you have talking with your parent with PD make you feel less close to them?					

Subject #6 feels that there are two parts to this question; thinking about problems talking, and then whether these make them feel less close to parent.

Subject #7 states they do not have any 'problems'. Require non-response option?

Subject #8 comments that this question appears the same as item 26 but in reverse. Remove?

Remove item

***

31.	Resentful about any changes in your parent's behavior as a result of PD, such as being impatient?					

Subject #6 found this question slightly more difficult to answer because of the example given, i.e. impatience, and suggests question would be easier without example.

Subject #7 feels impatience / frustration is a good example when asked.

Subject #8 suggests removing the example of impatience.

Remove example.

Replace 'resentful' with 'annoyed' as per adolescent version.

***

32.	Embarrassed by the effects of PD on your parent?					

Subject #7 hesitated to answer this question as was unsure in what context the question is being asked, i.e. unfamiliar social situations, or everyday situations.

Judged to be 'one-off' – no action taken.

***

Changes in yourself

How often do you feel:	Never	Rarely	Some-times	Often	All the time
33. More mature as a result of your parents PD?					

Subject #6 states that this was the case when younger, but has no affect now on maturity. Needs clarification re-wording?

Subject #7 suggests the word 'mature' is inappropriate for adult participants. Perhaps past tense, i.e. '...did you feel'.

Subject #8 suggests replacing 'mature' with 'responsible'.

Remove Item – inappropriate language, and components of maturity already covered (i.e. independence, responsibility).

34.	More understanding and sympathetic of other peoples' illness and disability as a result of your parent's PD?					

+++

+++ DM & CS note question still double-barrelled – remove 'sympathetic'.

***

35.	That you cope better with difficult problems as a result of your parent's PD?					

Subject #6 suggests dropping 'as a result of your parent's PD', as they cannot attribute their coping ability to parent's PD.

Subject #7 feels their coping skills were present before parent's PD.

As per adolescent version, alter question to 'in the last two weeks how often have you felt you coped well with difficult problems?'

Add non-response option - may not have experienced any problems

***

36.	That as a result of your parent's PD you are better at finding ways to deal with problems?					

Subject #6 again suggests dropping 'as a result of your parent's PD', as they cannot attribute their problem solving skills to parent's PD.

Subject #7 feels their problem solving skills were present before parent's PD.

As per adolescent version, remove item – difficult to answer and considered too similar to item 35.

Your future

To what extent:	Ext-remely	Very much	Fairly	Not much	Not at all
37. Are you concerned that your parent's PD will affect <u>your independence in the future?</u>					

Subject #7 found this question hard to answer as they were unsure to what extent they would be affected.

Judged to be 'one-off' – no action taken.

38.	Do you feel your parent's PD will affect when you make a decision to leave home? NA					

Subject #6, although not applicable now, states that retrospectively their parent's PD made them want to leave early!

Judged to be 'one-off' – no action taken.

39.	Do you feel <u>uncertain</u> about the future because of your parent's PD?					

Subject #6 found this difficult to answer as didn't know whether referring to them or their parent. Suggests changing **'the** future' to **'your** future'.

One-off – alteration would make no difference.

Subject #8 comments they are fearful they might develop PD. Not really what question is aiming at.

Separate question on developing PD to be incorporated

40.	Do you feel that your own future may be different than it otherwise might have been because of your parent's PD?					

Subject #6 repeated back the gist of this question.

No action necessary

Impact of PD on you and your family

To what extent do you feel that:	Ext-remely	Very much	Fairly	Not much	Not at all
41. Your parent's PD affects <u>your own</u> daily routine?					

Subject #6 states parent's PD doesn't affect them daily as doesn't speak to parent daily, due to distance from parent's home.

See item 42.

***

42.	Your parent's PD affects the life of your whole family?					

Subject #6 feels that this question is very much dependent on how far you live away from your parent with PD and that if the rest of the family lives some distance away from the ill parent the affect is only apparent when visiting. Add distance from parent's home to demographics?

Record distance living from parents home in demographics section of questionnaire booklet.

***

43.	Living in the family home is more difficult now than before your parent with PD became unwell? NA					

***

44.	Having a parent with PD affects your family financially?					

Subject #7 asks whether this refers to her own immediate family (i.e. husband, daughter, or to wider family also (i.e. father, mother, sister)? Clarification required?

Judged to be 'one-off' – no action taken.

***

***SECTION B**: Please answer* **YES** *or* **No** *to these questions.*

Information for you

		YES	NO
45.	Do you have all the information you need about PD?		
46.	Do you feel you know enough about what will happen in the future to your parent with PD?		
47.	Do you rely just on your parent(s) for information about PD? If no please write below from where else you receive information.		

	Support for you	YES	NO
48.	Do you feel that there is somebody you can talk to about PD if you want to?		

Subject #6 found this difficult to answer as was unsure whether the item relates to within or outside the family. For example, Subject #6 does inside the family, but not outside the family.

Irrelevant – no action taken.

Subject #7 was unsure who to base there answer on to this question, and based their answer on parent's need rather that own. Underline 'you'?

Appears participant has not read question properly - no action taken.

49.	Do you feel you have all the support you need from friends and family?		

50.	Do you have ways to deal with any anger / anxiety you may feel?		

Subject #7 found this question hard to answer and actually answered 'don't know' as states they 'don't know if anxious about life in general, and then something related to parent's PD makes it worse'. Not sure how relevant this is.

Participant appears to be getting overly philosophical - no action taken.

+++

+++ DM & CS note question still double-barrelled – remove anxiety.

51.	Does your parent with PD talk to you about the illness?		

52.	Would it help to have contact with people in a similar situation (*for example* through the Parkinson's Disease Society)?		

53.	Would it help you to have training in how to care for your parent with PD?		

54.	Do you think it would be helpful if you had the opportunity to have individual *counseling*?		

55.	Do you think it would help you to have counseling as a family?		

Subject #7 asks for clearer definition of family, and who the question involves. Clarification required?

Regarded as one-off as participant details unusual family structure.

Support for your parents		YES	NO
56.	Is outside help available in caring for your parent with PD?		

Subject #6 asks whether we are asking is help available, or are they aware that help is available?

Appears participant has not read question properly - no action taken.

Subject #7 asks whether the question refers to physical, emotional, or financial help. Clarification required?

Alter question to 'is help available in caring for your parent with PD (for example a professional carer)?'

57.	Do you think more help (*for example* meals on wheels, physiotherapy) should be provided to help care for your parent with PD?		

58.	Do you feel it would help <u>you</u> if you were able to talk to local services about any help provided for your parent with PD or your other parent?		

Subject #7 had to re-read this question as found it very 'wordy'.

Alter question to 'do you feel it would help <u>you</u> if you were able to talk to local services about any help provided (*for example* social services)?'

***SECTION C**: Finally, please mark on the scale below how you would rate **your overall quality of life**. If you think that your quality of life is really good you should mark near the right end of the scale. If, on the other hand, you think things are really bad, you should mark near left end of the scale.*

Appendix E: Validated Instruments Administered

Appendix E-i: Youth Quality of Life Instrument (YQOL-R)

1. **I keep trying, even if at first I don't succeed** *(please circle the number)*

NOT AT ALL	1	2	3	4	5	6	7	8	9	10	A GREAT DEAL

2. **I can handle most difficulties that come my way** *(please circle the number)*

NOT AT ALL	1	2	3	4	5	6	7	8	9	10	COMPLETELY

3. **I am able to do most things as well as I want** *(please circle the number)*

NOT AT ALL	1	2	3	4	5	6	7	8	9	10	COMPLETELY

4. **I feel good about myself** *(please circle the number)*

NOT AT ALL	1	2	3	4	5	6	7	8	9	10	COMPLETELY

5. **I feel I am important to others** *(please circle the number)*

NOT AT ALL	1	2	3	4	5	6	7	8	9	10	A GREAT DEAL

6. **I feel comfortable with my sexual feelings and behaviours** *(please circle the number)*

NOT AT ALL	1	2	3	4	5	6	7	8	9	10	COMPLETELY

7. **I have enough energy to do the things I want to do** *(please circle the number)*

NOT AT ALL	1	2	3	4	5	6	7	8	9	10	COMPLETELY

8. **I am pleased with how I look** *(please circle the number)*

NOT AT ALL	1	2	3	4	5	6	7	8	9	10	COMPLETELY

9. **I feel comfortable with the amount of stress in my life** *(please circle the number)*

NOT AT ALL	1	2	3	4	5	6	7	8	9	10	COMPLETELY

10. **I feel it is okay if I make mistakes** *(please circle the number)*

NOT AT ALL	1	2	3	4	5	6	7	8	9	10	COMPLETELY

11. **I feel my life has meaning** *(please circle the number)*

NOT AT ALL	1	2	3	4	5	6	7	8	9	10	COMPLETELY

12. **My personal beliefs give me strength** *(please circle the number)*

NOT AT ALL	1	2	3	4	5	6	7	8	9	10	A GREAT DEAL

13. **I feel adults treat me fairly** *(please circle the number)*

NOT AT ALL	1	2	3	4	5	6	7	8	9	10	COMPLETELY

14. **I feel I am getting the right amount of attention from my family** *(please circle the number)*

NOT AT ALL | 1 2 3 4 5 6 7 8 9 10 | COMPLETELY

15. **I feel understood by my parents or guardians** *(please circle the number)*

NOT AT ALL | 1 2 3 4 5 6 7 8 9 10 | COMPLETELY

16. **I feel useful and important to my family** *(please circle the number)*

NOT AT ALL | 1 2 3 4 5 6 7 8 9 10 | A GREAT DEAL

17. **I feel my family cares about me** *(please circle the number)*

NOT AT ALL | 1 2 3 4 5 6 7 8 9 10 | A GREAT DEAL

18. **My family encourages me to do my best** *(please circle the number)*

NOT AT ALL | 1 2 3 4 5 6 7 8 9 10 | A GREAT DEAL

19. **I feel I am getting along with my parents or guardians** *(please circle the number)*

NOT AT ALL | 1 2 3 4 5 6 7 8 9 10 | COMPLETELY

20. **I feel my parents or guardians allow me to participate in important decisions which affect me** *(please circle the number)*

NOT AT ALL | 1 2 3 4 5 6 7 8 9 10 | COMPLETELY

21. **I feel alone in my life** *(please circle the number)*

NOT AT ALL | 1 2 3 4 5 6 7 8 9 10 | A GREAT DEAL

22. **I try to be a role model for others** *(please circle the number)*

NOT AT ALL | 1 2 3 4 5 6 7 8 9 10 | A GREAT DEAL

23. **I can tell my friends how I really feel** *(please circle the number)*

NOT AT ALL | 1 2 3 4 5 6 7 8 9 10 | COMPLETELY

24. **I am happy with the friends I have** *(please circle the number)*

NOT AT ALL | 1 2 3 4 5 6 7 8 9 10 | COMPLETELY

25. **I am satisfied with my social life** *(please circle the number)*

NOT AT ALL | 1 2 3 4 5 6 7 8 9 10 | COMPLETELY

26. **I feel I can take part in the same activities as others my age** *(please circle the number)*

NOT AT ALL | 1 2 3 4 5 6 7 8 9 10 | COMPLETELY

27. **People my age treat me with respect** *(please circle the number)*

NOT AT ALL | 1 2 3 4 5 6 7 8 9 10 | COMPLETELY

28. **I feel left out because of who I am** *(please circle the number)*

NOT AT ALL | 1 2 3 4 5 6 7 8 9 10 | A GREAT DEAL

29. **I feel my life is full of interesting things to do** *(please circle the number)*

NOT AT ALL | 1 2 3 4 5 6 7 8 9 10 | A GREAT DEAL

30. **I like trying new things** *(please circle the number)*

NOT AT ALL | 1 2 3 4 5 6 7 8 9 10 | A GREAT DEAL

31. **I like my neighbourhood** *(please circle the number)*

NOT AT ALL | 1 2 3 4 5 6 7 8 9 10 | A GREAT DEAL

32. **I look forward to the future** *(please circle the number)*

NOT AT ALL | 1 2 3 4 5 6 7 8 9 10 | A GREAT DEAL

33. **My family has enough money to live a decent life** *(please circle the number)*

NOT AT ALL | 1 2 3 4 5 6 7 8 9 10 | COMPLETELY

34. **I feel safe when I am home** *(please circle the number)*

NOT AT ALL | 1 2 3 4 5 6 7 8 9 10 | COMPLETELY

35. **I feel I am getting a good education** *(please circle the number)*

NOT AT ALL | 1 2 3 4 5 6 7 8 9 10 | COMPLETELY

36. **I know how to get the information that I need** *(please circle the number)*

NOT AT ALL | 1 2 3 4 5 6 7 8 9 10 | COMPLETELY

37. **I enjoy learning new things** *(please circle the number)*

NOT AT ALL | 1 2 3 4 5 6 7 8 9 10 | A GREAT DEAL

38. **I feel safe when I am at school** *(please circle the number)*

NOT AT ALL | 1 2 3 4 5 6 7 8 9 10 | COMPLETELY

39. **I enjoy life** *(please circle the number)*

NOT AT ALL | 1 2 3 4 5 6 7 8 9 10 | A GREAT DEAL

40. **I am satisfied with the way my life is now** *(please circle the number)*

NOT AT ALL | 1 2 3 4 5 6 7 8 9 10 | COMPLETELY

41. **I feel life is worthwhile** *(please circle the number)*

NOT AT ALL | 1 2 3 4 5 6 7 8 9 10 | COMPLETELY

Appendix E-ii: Birleson Depression Self Rating Scale (DSRS)

	Most of the time	Some-times	Never
1. I look forward to things as much as I used to			
2. I sleep very well			
3. I feel like crying			
4. I like to go out with my friends			
5. I feel like running away			
6. I get stomach aches			
7. I have lots of energy			
8. I enjoy my food			
9. I can stick up for myself			
10. I think life isn't worth living			
11. I am good at the things I do			
12. I enjoy the things I do as much as I used to			
13. I like talking with my family			
14. I have horrible dreams			
15. I feel very lonely			
16. I am easily cheered up			
17. I feel so sad I can hardly stand it			
18. I feel very bored			

Appendix E-iii: Rosenberg Self-Esteem Questionnaire (SEQ)

	Strongly agree	Agree	Disagree	Strongly Disagree
1. On the whole I am satisfied with myself				
2. At times I think I am no good at all				
3. I feel that I have a number of good qualities				
4. I am able to do things as well as most other people				
5. I feel I do not have too much to be proud of				
6. I certainly feel useless at times				
7. I feel that I am a person of worth, at least on an equal plane with others				
8. I wish I could have more respect for myself				
9. All in all I am inclined to feel that I am a failure				
10. I take a positive attitude towards myself				

Appendix E-iv: Parentification Questionnaire – Youth (PQ-Y)

1.	I often have to do other family members' chores.	*Y*	*N*
2.	I seem to get the blame for most of what happens in my family.	*Y*	*N*
3.	I often feel like an outsider in my family.	*Y*	*N*
4.	I feel there's enough problems at home; so I don't want to cause more.	*Y*	*N*
5.	I'm often asked to do more than my share of the work in my family.	*Y*	*N*
6.	I often feel like a referee in my family.	*Y*	*N*
7.	It often seems that no one in my family pays attention to my feelings.	*Y*	*N*
8.	It's OK to tell people in my family how I feel.	*Y*	*N*
9.	I'm told that I act older than my age.	*Y*	*N*
10.	I feel I'm asked too often to take care of some other family member.	*Y*	*N*
11.	It seems that people in my family bring me their problems.	*Y*	*N*
12.	I often do extra housework to help my parents.	*Y*	*N*
13.	My family notices that I give-up a lot of things for them.	*Y*	*N*
14.	My parents are very helpful to me when I have a problem.	*Y*	*N*
15.	I feel my family understands me pretty well.	*Y*	*N*
16.	My parents seem to disagree about everything.	*Y*	*N*
17.	I often feel more like an adult than a child in my family.	*Y*	*N*
18.	The chores are shared equally in my family.	*Y*	*N*
19.	I do a lot of the cooking at home.	*Y*	*N*
20.	I have to help a lot with the family bills.	*Y*	*N*

Appendix E-v: Family Crisis Orientated Personal Evaluation Scales (F-COPES)

When we face problems or difficulties in our family, we respond by:	Strongly disagree	Moderately disagree	Neither agree nor disagree	Moderately agree	Strongly agree
1. Sharing our difficulties with relatives.	1	2	3	4	5
2. Seeking encouragement and support from friends.	1	2	3	4	5
3. Knowing we have the power to solve major problems.	1	2	3	4	5
4. Seeking information and advice from persons in other families who have faced the same or similar problems.	1	2	3	4	5
5. Seeking advice from relatives (grandparents, etc.).	1	2	3	4	5
6. Seeking assistance from community agencies and programs designed to help families in our situation.	1	2	3	4	5
7. Knowing that we have the strength within our own family to solve our problems.	1	2	3	4	5
8. Receiving gifts and favours from neighbours (e.g. food, taking in mail, etc.).	1	2	3	4	5
9. Seeking information and advice from the family doctor.	1	2	3	4	5
10. Asking neighbours for favours and assistance.	1	2	3	4	5
11. Facing the problems 'head on' and trying to get a solution right away.	1	2	3	4	5
12. Watching television.	1	2	3	4	5
13. Showing that we are strong.	1	2	3	4	5
14. Attending church services.	1	2	3	4	5
15. Accepting stressful events as a fact of life.	1	2	3	4	5
16. Sharing concerns with close friends.	1	2	3	4	5
17. Knowing luck plays a big part in how well we are able to solve family problems.	1	2	3	4	5
18. Exercising with friends to stay fit and reduce tension.	1	2	3	4	5
19. Accepting that difficulties occur unexpectedly.	1	2	3	4	5
20. Doing things with relatives (get-togethers, dinners, etc.).	1	2	3	4	5
21. Seeking professional counselling and help for family difficulties.	1	2	3	4	5
22. Believing we can handle our own problems.	1	2	3	4	5
23. Participating in church activities.	1	2	3	4	5
24. Defining the family problem in a more positive way so that we do not become too discouraged.	1	2	3	4	5
25. Asking relatives how they feel about problems we face.	1	2	3	4	5
26. Feeling that no matter what we do to prepare, we will have difficulty handling problems.	1	2	3	4	5
27. Seeking advice from a priest or vicar.	1	2	3	4	5
28. Believing if we wait long enough, the problem will go away.	1	2	3	4	5
29. Sharing problems with neighbours.	1	2	3	4	5
30. Having faith in God.	1	2	3	4	5

Appendix E-vi: Inventory of Parent and Peer Attachment (IPPA)

	Almost always or always true	Often true	Some-times true	Seldom true	Almost never or never true
1. My parents respect my feelings.					
2. I feel my parents are successful as parents.					
3. I wish I had different parents.					
4. My parents accept me as I am.					
5. I have to rely on myself when I have a problem to solve.					
6. I like to get my parents point of view on things I'm concerned about.					
7. I feel it's no use letting my feelings show.					
8. My parents sense when I'm upset about something.					
9. Talking over my problems with my parents makes me feel ashamed or foolish.					
10. My parents expect too much from me.					
11. I get upset easily at home.					
12. I get upset a lot more than my parents know about.					
13. When we discuss things my parents consider my point of view.					
14. My parents trust my judgment.					
15. My parents have their own problems, so I don't bother them with mine.					
16. My parents help me to understand myself better.					
17. I tell my parents about my problems and troubles.					
18. I feel angry with my parents.					
19. I don't get much attention at home.					
20. My parents encourage me to talk about my difficulties.					
21. My parents understand me.					
22. I don't know whom I can depend on these days.					
23. When I am angry about something, my parents try to be understanding.					
24. I trust my parents.					
25. My parents don't understand what I'm going through these days.					
26. I can count on my parents when I need to get something off my chest.					
27. I feel that no one understands me.					
28. If my parents know something is bothering me, they ask me about it.					

Appendix E-vii: Family Environment Scale (FES)

1	Family members really help and support one another.	T F	2	Family members often keep their feelings to themselves.	T F
3	We fight a lot in our family.	T F	4	We don't do things on our own very often in our family.	T F
5	We feel it is important to be the best at whatever you do.	T F	6	We often talk about political and social problems.	T F
7	We spend most weekends and evenings at home.	T F	8	Family members attend church, synagogue, or Sunday School fairly often.	T F
9	Activities in our family are pretty carefully planned.	T F	10	Family members are rarely ordered around.	T F
11	We often seem to be killing time at home.	T F	12	We say anything we want to around home.	T F
13	Family members rarely become openly angry.	T F	14	In our family, we are strongly encouraged to be independent.	T F
15	Getting ahead in life is very important in our family.	T F	16	We rarely go to lectures plays or concerts.	T F
17	Friends often come over for dinner or to visit.	T F	18	We don't say prayers in our family.	T F
19	We are generally very neat and orderly.	T F	20	There are very few rules to follow in our family.	T F
21	We put a lot of energy into what we do at home.	T F	22	It's hard to 'blow off steam' at home without upsetting somebody.	T F
23	Family members sometimes get so angry they throw things.	T F	24	We think for ourselves in our family.	T F
25	How much money a person makes is very important to us.	T F	26	Learning about new and different things is very important in our family.	T F
27	Nobody in our family is active in sports, football, bowling, etc.	T F	28	We often talk about the religious meaning of Christmas, Passover, or other holidays.	T F
29	It's often hard to find things when you need them in our household.	T F	30	There is one family member who makes most of the decisions.	T F
31	There is a feeling of togetherness in our family	T F	32	We tell each other about our personal problems	T F
33	Family members hardly ever lose their tempers	T F	34	We come and go as we want in our family	T F
35	We believe in competition and 'may the best man win'.	T F	36	We are not interested in cultural activities.	T F
37	We often go to the movies, sports events, camping, etc.	T F	38	We don't believe in heaven or hell.	T F
39	Being on time is very important in our family.	T F	40	There are set ways of doing things at home.	T F
41	We rarely volunteer when something has to be done at home.	T F	42	If we feel like doing something on the spur of the moment we often just pick up and go	T F

43	Family members often criticize each other.	T F	44	There is very little privacy in our family.	T F
45	We always strive to do things just a little better the next time.	T F	46	We rarely have intellectual discussions.	T F
47	Everyone in our family has a hobby or two.	T F	48	Family members have strict ideas about what is right and wrong.	T F
49	People change their minds often in our family.	T F	50	There is a strong emphasis on following rules in our family.	T F
51	Family members really back each other up.	T F	52	Someone usually gets upset if you complain in our family.	T F
53	Family members sometimes hit each other.	T F	54	Family members almost always rely on themselves when a problem comes up.	T F
55	Family members rarely worry about job promotions, school grades, etc.	T F	56	Someone in our family plays a musical instrument.	T F
57	Family members are not very involved in recreational activities outside work or school.	T F	58	We believe there are some things you just have to take on faith.	T F
59	Family members make sure their rooms are neat.	T F	60	Everyone has an equal say in family decisions.	T F
61	There is very little group spirit in our family.	T F	62	Money and paying bills is openly talked about in our family.	T F
63	If there's a disagreement in our family, we try hard to smooth things over and keep the peace	T F	64	Family members strongly encourage each other to stand up for their rights.	T F
65	In our family, we don't try that hard to succeed.	T F	66	Family members often go the library.	T F
67	Family members sometimes attend courses or take lessons for some hobby or interest (outside of school)	T F	68	In our family each person has different ideas about what is right and wrong.	T F
69	Each person's duties are clearly defined in our family.	T F	70	We can do whatever we want in our family.	T F
71	We really get along well with each other.	T F	72	We are usually careful about what we say to each other.	T F
73	Family members often try to one-up or out-do each other.	T F	74	It's hard to be by yourself without hurting someone's feelings in our household.	T F
75	"Work before play" is the rule in our family.	T F	76	Watching TV is more important than reading in our family.	T F
77	Family members go out a lot.	T F	78	The bible is a very important book in our home.	T F
79	Money is not handled very carefully in our family.	T F	80	Rules are pretty inflexible in our household.	T F
81	There is plenty of time and attention for everyone in our family.	T F	82	There are a lot of spontaneous discussions in our family.	T F
83	In our family we believe you don't ever get anywhere by raising your voice.	T F	84	We are not really encouraged to speak up for ourselves in our family.	T F
85	Family members are often compared with others as to how well they are doing at work or school	T F	86	Family members really like music, art and literature.	T F
87	Our main form of entertainment is watching TV or listening to the radio.	T F	88	Family members believe that if you sin you will be punished.	T F
89	Dishes are usually done immediately after eating.	T	90	You can't get away with much in our family.	T

Appendix E-viii: Social Support Scale for Children (SSSC)

	Really true for me	Sort of true for me				Sort of true for me	Really true for me
1.	☐	☐	Some kids have parents who **don't** really **understand** them	BUT	Other kids have parents who really **do** understand them	☐	☐
2.	☐	☐	Some kids have classmates who like them the way they are	BUT	Other kids have classmates who wish they were **different**	☐	☐
3.	☐	☐	Some kids have a teacher who **helps** them if they are **upset** and have a problem	BUT	Other kids **don't** have a teacher who helps them if they are upset and have a problem	☐	☐
4.	☐	☐	Some kids have a close friend who they can tell **problems** to	BUT	Other kids **don't** have a close friend who they can tell problems to	☐	☐
5.	☐	☐	Some kids have parents who **don't** seem to want to hear about their children's problems	BUT	Other kids have parents who **do** want to **listen** to their children's problems	☐	☐
6.	☐	☐	Some kids have classmates they can become friends with	BUT	Other kids **don't** have classmates they can become friends with	☐	☐
7.	☐	☐	Some kids **don't** have a teacher who **helps** them to do their very best	BUT	Other kids **do** have a teacher who **helps** them to do their very best	☐	☐
8.	☐	☐	Some kids have a close friend who really understands them	BUT	Other kids **don't** have a close friend who understands them	☐	☐
9.	☐	☐	Some kids have parents who **care** about their feelings	BUT	Other kids have parents who **don't** seem to care very much about their children's feelings	☐	☐
10.	☐	☐	Some kids have classmates who sometimes make fun of them	BUT	Other kids **don't** have classmates who make fun of them	☐	☐
11.	☐	☐	Some kids **do** have a teacher who **cares** about them	BUT	Other kids **don't** have a teacher who cares about them	☐	☐
12.	☐	☐	Some kids have a close friend who they can talk to about things that bother them	BUT	Other kids **don't** have a close friend who they can talk to about things that bother them	☐	☐
13.	☐	☐	Some kids have parents who treat their children like a **person** who really matters	BUT	Other kids have parents who **don't** usually treat their children like a person who really matters	☐	☐
14.	☐	☐	Some kids have classmates who pay attention to what they say	BUT	Other kids have classmates who usually don't pay attention to what they say	☐	☐
15.	☐	☐	Some kids **don't** have a teacher who is fair to them	BUT	Other kids **do** have a teacher who is fair to them	☐	☐
16.	☐	☐	Some kids **don't** have a close friend who they like to spend time with	BUT	Other kids **do** have a close friend who they like to spend time with	☐	☐
17.	☐	☐	Some kids have parents who like them the **way they are**	BUT	Other kids have parents who wish their children were **different**	☐	☐
18.	☐	☐	Some kids **don't** get asked to play in games with classmates very often	BUT	Other kids **often** get asked to play in games by their classmates	☐	☐
19.	☐	☐	Some kids **don't** have a teacher who cares if they feel bad	BUT	Other kids **do** have a teacher who cares if they feel bad	☐	☐
20.	☐	☐	Some kids **don't** have a close friend who really **listens** to what they say	BUT	Other kids **do** have a close friend who really listens to what they say	☐	☐
21.	☐	☐	Some kids have parents who **don't** act like what their children do is **important**	BUT	Other kids have parents who **do** act like what their children do is important	☐	☐
22.	☐	☐	Some kids often spend break-time being **alone**	BUT	Other kids spend break-time playing with their classmates	☐	☐
23.	☐	☐	Some kids have a teacher who treats them like a **person**	BUT	Other kids **don't** have a teacher who treats them like a person	☐	☐
24.	☐	☐	Some kids **don't** have a close friend who cares about their feelings	BUT	Other kids **do** have a close friend who cares about their feelings	☐	☐

Appendix E-ix: EUROQoL-5D

Mobility

I have no problems walking about

I have some problems walking about

I am confined to bed

Self-Care

I have no problems with self-care

I have some problems with washing or dressing myself

I am unable to wash or dress myself

Usual Activities (e.g. work, study, housework, family or leisure activities)

I have no problems with performing my usual activities

I have some problems with performing my usual activities

I am unable to perform my usual activities

Pain / Discomfort

I have no pain or discomfort

I have moderate pain or discomfort

I have extreme pain or discomfort

Anxiety / Depression

I am not anxious or depressed

I am moderately anxious or depressed

I am extremely anxious or depressed

EuroQol Thermometer

To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked by 100 and the worst state you can imagine is marked by 0.

We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your current health state is.

Your own health state today

Best Imaginable Health State

100
+
+
+
90
+
+
+
80
+
+
+
70
+
+
+
60
+
+
+
50
+
+
+
40
+
+
+
30
+
+
+
20
+
+
+
10
+
+
+
0

Worst Imaginable Health State

Appendix E-x: Beck Depression Inventory (BDI)

1. **0** I do not feel sad
   1 I feel sad
   2 I feel sad all of the time and can't snap out of it
   3 I am so sad or unhappy that I can't stand it

2. **0** I am not particularly discouraged about the future
   1 I feel discouraged about the future
   2 I feel I have nothing to look forward to
   3 I feel that the future is hopeless and that things cannot improve

3. **0** I do not feel like a failure
   1 I feel I have failed more than the average person
   2 As I look back on my life, all I can see is a lot of failures
   3 I feel I am a complete failure as a person

4. **0** I get as much satisfaction out of things as I used to
   1 I don't enjoy things the way I used to
   2 I don't get real satisfaction out of things anymore
   3 I am dissatisfied or bored with everything

5. **0** I don't feel particularly guilty
   1 I feel guilty a good part of the time
   2 I feel quite guilty most of the time
   3 I feel guilty all of the time

6. **0** I don't feel I am being punished
   1 I feel I may be punished
   2 I expect to be punished
   3 I feel I am being punished

7. **0** I don't feel disappointed in myself
   1 I am disappointed in myself
   2 I am disgusted with myself
   3 I hate myself

8. **0** I don't feel I am worse than anyone else
   1 I am critical of myself for my weakness or mistakes
   2 I blame myself all the time for my faults
   3 I blame myself for everything that happens

9. **0** I don't have any thoughts of killing myself
   1 I have thoughts of killing myself, but I wouldn't carry them out
   2 I would like to kill myself
   3 I would kill myself if I had the chance

10. **0** I don't cry any more than usual
    1 I cry more now than I used to
    2 I cry all of the time now
    3 I used to be able to cry, but now I can't cry even though I want to

11. **0** I am no more irritated now than I ever am
    1 I get annoyed or irritated more easily now than I used to
    2 I feel irritated all of the time now
    3 I don't get irritated at all by the things that used to irritate me

12. **0** I have not lost interest in other people
    1 I am less interested in other people than I used to be
    2 I have lost most of my interest in other people
    3 I have lost all of my interest in other people

13. **0** I make decisions about as well as I ever could
    1 I put off making decisions more than I used to
    2 I have greater difficulty in making decisions than before
    3 I can't make decisions at all anymore

14. **0** I don't feel I look worse than I used to
    1 I am worried that I am looking old or unattractive
    2 I feel that there are permanent changes in my appearance that make me look unattractive
    3 I believe that I look ugly

15. **0** I can work about as well as before
    1 It takes an extra effort to get started on doing something
    2 I have to push myself very hard to do anything
    3 I can't do any work at all

16. **0** I can sleep as well as usual
    1 I don't sleep as well as I used to
    2 I wake up 1-2 hours earlier than usual and find it hard to get back to sleep
    3 I wake up several hours earlier than I used to and cannot get back to sleep

17. **0** I don't get tired any more than usual
    1 I get tired more easily than I used to
    2 I get tired from doing almost anything
    3 I am too tired to do anything

18. **0** My appetite is no worse than usual
    1 My appetite is not as good as it used to be
    2 My appetite is much worse now
    3 I have no appetite at all now

19. **0** I haven't lost much weight, if any lately
    1 I have lost more than 5 pounds
    2 I have lost more than 10 pounds
    3 I have lost more than 15 pounds

    I am purposely trying to lose weight by eating less
    YES ..... NO .....

20. **0** I am no more worried about my health than usual
    1 I am worried about my physical problems such as aches and pains, upset stomach or constipation
    2 I am very worried about physical problems and it is very difficult to think of much else
    3 I am so worried about my physical problems that I cannot think of anything else

21. **0** I have not noticed any recent change in my interest in sex
    1 I am less interested in sex than I used to be
    2 I am much less interested in sex now
    3 I have lost interest in sex completely

Appendix xi: Parentification Questionnaire – Adult (PQ-A)

		True	False
1.	I rarely found it necessary for me to do other family members chores.		
2.	At times I felt I was the only one my mother/father could turn to.		
3.	My family members hardly ever looked to me for advice.		
4.	In my family I often felt called upon to do more than my share.		
5.	I often felt like an outsider in my family.		
6.	I felt most valuable in my family when someone confided in me.		
7.	It seemed like there were enough problems at home without my causing more.		
8.	In my family I thought it best to let people work out their problems on their own.		
9.	I often resented being asked to do certain kinds of jobs.		
10.	In my family it seemed that I was usually the one who ended up being responsible for most of what happened.		
11.	In my mind, the welfare of my family was my first priority.		
12.	If someone in my family had a problem, I was rarely the one they could turn to for help.		
13.	I was frequently responsible for the physical care of some member of my family, i.e. washing, feeding, dressing, etc.		
14.	My family was not the kind in which people took sides.		
15.	It often seemed that my feelings weren't taken into account in my family.		
16.	I often found myself feeling down for no particular reason that I could think of.		
17.	In my family there were certain family members I could handle better than anyone else.		
18.	I often preferred the company of people older than me.		
19.	I hardly ever felt let down by members of my family.		
20.	I hardly ever got involved in conflicts between my parents.		
21.	I usually felt comfortable telling family members how I felt.		
22.	I rarely worried about people in my family.		
23.	As a child I was often described as mature for my age.		
24.	In my family I often felt like a referee.		

	True	False
25. In my family I initiated most recreational activities.		
26. It seemed like family members were always bringing me their problems.		
27. My parents had enough to do without worrying about housework as well.		
28. In my family I often made sacrifices that went unnoticed by other family members.		
29. My parents were very helpful when I had a problem.		
30. If a member of my family were upset, I would almost always become involved in some way.		
31. I could usually manage to avoid doing housework.		
32. I believe that most people understood me pretty well, particularly members of my family.		
33. As a child, I wanted to make everyone in my family happy.		
34. My parents rarely disagreed on anything important.		
35. I often felt more like an adult than a child in my family.		
36. I was more likely to spend time with friends than with family members.		
37. Other members of my family rarely needed me to take care of them		
38. I was very uncomfortable when things weren't going well at home.		
39. All things considered, responsibilities were shared equally in my family.		
40. In my house I hardly ever did the cooking.		
41. I was very active in the management of my family's financial affairs.		
42. I was at my best in times of crisis.		

Appendix E-xii: Social Support Questionnaire Short R (SSQSR)

***1.** Whom can you really count on to be dependable when you need help?*

No one	1.	2.	3.
	4.	5.	6.
	7.	8.	9.

How satisfied?

6 – Very satisfied	5 – Fairly satisfied	4 – A little satisfied	3 – A little dissatisfied	2 – fairly dissatisfied	1 – very dissatisfied

***2.** Whom can you really count on to help you feel more relaxed when you are under pressure or tense?*

No one	1.	2.	3.
	4.	5.	6.
	7.	8.	9.

How satisfied?

6 – Very satisfied	5 – Fairly satisfied	4 – A little satisfied	3 – A little dissatisfied	2 – fairly dissatisfied	1 – very dissatisfied

***3.** Who accepts you totally, including both your worst and your best points?*

No one	1.	2.	3.
	4.	5.	6.
	7.	8.	9.

How satisfied?

6 – Very satisfied	5 – Fairly satisfied	4 – A little satisfied	3 – A little dissatisfied	2 – fairly dissatisfied	1 – very dissatisfied

***4.** Whom can you count on to care about you, regardless of what is happening to you?*

No one	1.	2.	3.
	4.	5.	6.
	7.	8.	9.

How satisfied?

6 – Very satisfied	5 – Fairly satisfied	4 – A little satisfied	3 – A little dissatisfied	2 – fairly dissatisfied	1 – very dissatisfied

***5.** Whom can you count on to help you feel better when you are feeling generally down-in-the-dumps?*

No one	1.	2.	3.
	4.	5.	6.
	7.	8.	9.

How satisfied?

6 – Very satisfied	5 – Fairly satisfied	4 – A little satisfied	3 – A little dissatisfied	2 – fairly dissatisfied	1 – very dissatisfied

***6.** Whom can you count on to console you when you are very upset?*

No one	1.	2.	3.
	4.	5.	6.
	7.	8.	9.

How satisfied?

6 – Very satisfied	5 – Fairly satisfied	4 – A little satisfied	3 – A little dissatisfied	2 – fairly dissatisfied	1 – very dissatisfied

Appendix E-xiii: Self-administered Schwabb & England Measure of Disability

Instructions: ***Please circle which answer most correctly describes your level of independence.***

10	I am completely independent. I am **able to do all chores** without slowness, difficulty, or impairment, and I am **unaware of any difficulties**.
9	I am completely independent, and I am **able to do all chores**. However there is **some slowness**, difficulty or impairment, and chores might take twice as long.
8	I am completely independent in **most** chores, but I am aware of difficulties and slowness and **chores usually take twice as long**.
7	I am **not** completely independent. Some chores take three to four times as long, and I must **spend a large part of the day with chores**.
6	I depend on other people **to some degree**. I can do most chores, but exceedingly slowly and with much effort. **Some chores are impossible**.
5	I depend on other people for **help with half of the chores. I have difficulty with everything**.
4	I am very dependent on other people. I can assist with all chores, but **can do few chores alone**.
3	With effort, now and then I can do a **few chores alone** or begin alone. I **need much help**.
2	I can do nothing alone, but I can be a **slight help with some chores**.
1	I am **totally dependent**, and more or less helpless.
0	I have no control over swallowing, bladder control, and bowel functions, and I am **bed-ridden**.

Appendix E-xvi: Self-Report Barthel Index (SRBI)

Instructions: *These are some questions about your ability to look after yourself. They might not seem to apply to you; please answer them all. Tick one box in each section*

Bathing

In the bath or shower, do you.....manage on your own? ☐
need help getting in and out? ☐
need other help? ☐
never have a bath or shower? ☐
need to be washed in bed? ☐

Stairs

Do you climb stairs at home.....without any help? ☐
with someone carrying your frame? ☐
with someone encouraging you? ☐
with physical help? ☐
not at all? ☐
don't have stairs? ☐

Dressing

Do you get dressed.....without any help? ☐
just with help with buttons? ☐
with someone helping you most of the time? ☐

Mobility

Do you walk indoors.....without any help apart from a frame? ☐
with one person watching over you? ☐
with one person helping you? ☐
with more than one person helping you? ☐
not at all? ☐
Or do you use a wheelchair independently? ☐

Transfer

Do you move from bed to chair.....on your own? ☐
with a little help from one person? ☐
with a lot of help from one or more people? ☐
not at all? ☐

Feeding

Do you eat food.....without any help? ☐
with help cutting food or spreading butter? ☐
with more help? ☐

Toilet use

Do you use the toilet or commode.....without any help? ☐
with some help but can do something? ☐
with quite a lot of help? ☐

Grooming

Do you brush your hair and teeth and wash your face.....without help? ☐
with help? ☐

Bladder

Are you incontinent of urine.....never? ☐
less than once a week? ☐
less than once a day? ☐
more often? ☐
Or do you have a catheter managed for you? ☐

Bowels

Do you soil yourself.....never? ☐
occasional accident? ☐
all the time? ☐
Or do you need someone to give you an enema? ☐

Appendix E-xv: National Statistics Socio-Economic Classification (NS-SEC)

Question 1 – Employee or self-employed

Do (did) you work as an employee or are (were) you self-employed?

Employee ☐

Self-employed with employees ☐

Self-employed / freelance without employees (go to question 4) ☐

Question 2 – Number of employees (Employees)

For employees: indicate below how many people work (worked) for your employer at the place where you work (worked).
For self-employed: indicate below how many people you employ (employed). Go to question 4 when you have completed this question.

1 to 24 ☐

25 or more ☐

Question 3 – Supervisory Status

Do (did) you supervise any other employees?
A supervisor or foreman is responsible for overseeing the work of other employees on a day-to-day basis

Yes ☐

No ☐

Question 4 – occupation

Please tick one box to show which **best** describes the sort of work you do.
(If you are not working now, please tick a box to show what you did in your last job).

PLEASE TICK ONE BOX ONLY

Modern professional occupations
such as: teacher - nurse - physiotherapist - social worker - welfare officer - artist - musician - police officer (sergeant or above) - software designer ☐ 1

Clerical and intermediate occupations
such as: secretary - personal assistant - clerical worker - office clerk - call centre agent - nursing auxiliary - nursery nurse ☐ 2

Senior managers or administrators
(usually responsible for planning, organising and co-ordinating work and for finance)
such as: finance manager - chief executive ☐ 3

Technical and craft occupations
such as: motor mechanic - fitter - inspector - plumber - printer - tool maker - electrician - gardener - train driver ☐ 4

Semi-routine manual and service occupations
such as: postal worker - machine operative - security guard - caretaker - farm worker - catering assistant - receptionist - sales assistant ☐ 5

Routine manual and service occupations
such as: HGV driver - van driver - cleaner - porter - packer - sewing machinist - messenger - labourer - waiter / waitress - bar staff ☐ 6

Middle or junior managers
such as: office manager - retail manager - bank manager - restaurant manager - warehouse manager - publican ☐ 7

Traditional professional occupations
such as: accountant - solicitor - medical practitioner - scientist - civil / mechanical engineer ☐ 8

Appendix F: Study Information Sheet & Consent Form

Institute of Neurology

Sobell Research Department of Motor Neuroscience and Movement Disorders

Head of Department: **Professor John Rothwell**

From: David Morley BSc MSc
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Fax: +44 (0)20 7278 9836
Email: D.Morley@ion.ucl.ac.uk

Institute of Neurology
Queen Square
London WC1N 3BG

Quality of Life in Children with an Ill Parent

You and your family are invited to participate in a research study conducted at the Institute of Neurology and the National Hospital for Neurology & Neurosurgery.

Aims of the Study:
The aim of the study is to learn more about the impact of having an ill parent on both young and adult children. Sometimes having a parent who is ill might lead to changes in a child's quality of life. For example, they might be asked to take part in looking after their unwell parent. This might mean they then have less time to spend with friends. Little is currently known about how this affects children either in the short or long-term.

How can we measure someone's quality of life, and why do it?
Social scientists such as psychologists have spent a number of years now developing questionnaires to measure different aspects of our health and well-being. Measuring 'quality of life' is a relatively new concept that has 'taken-off' in the last 10-15 years. What is important about quality of life is that it tells us how someone feels from **THEIR** point of view, and not just the point of view of others, for example, a doctor.

What we would like you to do during the study:
We would like to send each family member a booklet containing a number of different questionnaires. These tell us about aspects of your well-being such as self-esteem, depression, levels of support, and overall quality of life. The booklet will take approximately 1-2 hours to complete. We would like you to complete this alone and in your own time. A few weeks later we would like to ask you to complete one of the questionnaires for a second time. A counsellor, Dr Marjan Jahanshahi, will be available on 020 7837 3611 ext 3055, to discuss any issues or difficulties that might arise for family members during their participation in the study.

Your rights:
It is up to you to decide whether or not to take part. If you do decide to take part you are still free to withdraw at any time without giving a reason. A decision to withdraw or not to take part will not affect any care you might receive in the future. Details about you will be stored on a computer during this research project. All information about you will be treated as strictly confidential, and will only be used for research purposes. If any information is released this will be done so in coded form so that confidentiality is strictly maintained. Participation in this study will in no way affect your legal rights.

Contacts:
If you and other members of your family are willing to help with this research study, please each complete and return an enclosed consent form. Those under 18 must have their form signed by a parent or guardian. If your children have grown up and left home we would very much like them to take part also. If you would like to discuss the project further, or require more consent forms, please contact Mr David Morley at the Institute of Neurology on 020 7837 3611, ext 4467, or by email at D.Morley@ion.ucl.ac.uk.

Mr D Morley Dr M Jahanshahi Prof. N Quinn

THE NATIONAL HOSPITAL FOR NEUROLOGY
AND NEUROSURGERY

Queen Square, London WC1N 3BG
Telephone: 0171 837 3611
Fax: 0171 829 8720

CONSENT FORM - Confidential

Study: ***Quality of Life in Children with an Ill Parent***

Investigator: ***Mr David Morley***
Sobell Department of Motor Neuroscience and Movement Disorders,
Institute of Neurology, Queen Square, London. WC1N 3BG
Tel – 020 7837 3611, ext 4467
E-mail – D.Morley@ion.ucl.ac.uk

1. I confirm that I have read and understood the information sheet dated September 2002 (version 2) for the above study and have had the opportunity to ask questions should I need to. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐
3. I agree to take part in the above study. ☐

Name of participant	Date	Signature
Name of Parent or Guardian if under 18	Date	Signature
Researcher	Date	Signature

Appendix G: Missing Value Analysis

Missing Values: Youth QoL Scale					
Item No	Count	%	Item No	Count	%
1.	0	.0	22.	1	2.0
2.	0	.0	23.	0	.0
3.	1	2.0	24.	0	.0
4.	0	.0	25.	0	.0
5.	1	2.0	26.	0	.0
6.	4	7.8	27.	0	.0
7.	0	.0	28.	0	.0
8.	0	.0	29.	0	.0
9.	0	.0	30.	0	.0
10.	0	.0	31.	0	.0
11.	1	2.0	32.	0	.0
12.	2	3.9	33.	0	.0
13.	0	.0	34.	0	.0
14.	0	.0	35.	0	.0
15.	0	.0	36.	0	.0
16.	0	.0	37.	0	.0
17.	0	.0	38.	0	.0
18.	0	.0	39.	1	2.0
19.	0	.0	40.	0	.0
20.	0	.0	41.	1	2.0
21.	1	2.0			

Missing Values: Birleson Depression Self Rating Scale					
Item No	Count	%	Item No	Count	%
1.	0	.0	10.	0	.0
2.	0	.0	11.	0	.0
3.	0	.0	12.	0	.0
4.	0	.0	13.	0	.0
5.	0	.0	14.	0	.0
6.	0	.0	15.	0	.0
7.	0	.0	16.	0	.0
8.	0	.0	17.	0	.0
9.	0	.0	18.	0	.0

Missing Values: Self-Esteem Questionnaire					
Item No	Count	%	Item No	Count	%
1.	3	1.8	6.	3	1.8
2.	3	1.8	7.	3	1.8
3.	3	1.8	8.	3	1.8
4.	3	1.8	9.	3	1.8
5.	3	1.8	10.	3	1.8

Missing Values: Parentification Questionnaire - Youth					
Item No	Count	%	Item No	Count	%
1.	0	.0	11.	0	.0
2.	0	.0	12.	0	.0
3.	0	.0	13.	0	.0
4.	0	.0	14.	0	.0
5.	0	.0	15.	0	.0
6.	0	.0	16.	0	.0
7.	0	.0	17.	0	.0
8.	0	.0	18.	0	.0
9.	0	.0	19.	0	.0
10.	0	.0	20.	0	.0

Missing Values: Social Support Scale for Children					
Item No	Count	%	Item No	Count	%
1.	10	19.6	13.	10	19.6
2.	10	19.6	14.	10	19.6
3.	10	19.6	15.	10	19.6
4.	10	19.6	16.	10	19.6
5.	11	21.6	17.	10	19.6
6.	10	19.6	18.	10	19.6
7.	10	19.6	19.	10	19.6
8.	10	19.6	20.	10	19.6
9.	10	19.6	21.	10	19.6
10.	10	19.6	22.	10	19.6
11.	10	19.6	23.	10	19.6
12.	10	19.6	24.	10	19.6

Missing Values: Inventory of Parent & Peer Attachment					
Item No	Count	%	Item No	Count	%
1.	0	.0	15.	0	.0
2.	0	.0	16.	1	2.0
3.	0	.0	17.	0	.0
4.	0	.0	18.	0	.0
5.	0	.0	19.	1	2.0
6.	0	.0	20.	0	.0
7.	0	.0	21.	0	.0
8.	0	.0	22.	0	.0
9.	0	.0	23.	1	2.0
10.	0	.0	24.	0	.0
11.	0	.0	25.	0	.0
12.	0	.0	26.	1	2.0
13.	0	.0	27.	1	2.0
14.	0	.0	28.	1	2.0

Missing Values: EUROQOL					
Item No	Count	%	Item No	Count	%
1.	3	2.5	4.	3	2.5
2.	3	2.5	5.	3	2.5
3.	3	2.5	VAS	3	2.5

Missing Values: Beck Depression Inventory					
Item No	Count	%	Item No	Count	%
1.	4	3.4	12.	4	3.4
2.	4	3.4	13.	4	3.4
3.	4	3.4	14.	4	3.4
4.	4	3.4	15.	4	3.4
5.	4	3.4	16.	4	3.4
6.	4	3.4	17.	4	3.4
7.	4	3.4	18.	4	3.4
8.	4	3.4	19.	6	5.0
9.	4	3.4	20.	4	3.4
10.	4	3.4	21.	4	3.4
11.	4	3.4			

Missing Values: Parentification Questionnaire - Adult					
Item No	Count	%	Item No	Count	%
1.	2	1.7	22.	2	1.7
2.	2	1.7	23.	4	3.4
3.	2	1.7	24.	2	1.7
4.	2	1.7	25.	3	2.5
5.	2	1.7	26.	2	1.7
6.	4	3.4	27.	4	3.4
7.	3	2.5	28.	2	1.7
8.	3	2.5	29.	3	2.5
9.	2	1.7	30.	3	2.5
10.	3	2.5	31.	2	1.7
11.	2	1.7	32.	2	1.7
12.	3	2.5	33.	2	1.7
13.	3	2.5	34.	2	1.7
14.	2	1.7	35.	2	1.7
15.	2	1.7	36.	2	1.7
16.	2	1.7	37.	2	1.7
17.	2	1.7	38.	3	2.5
18.	2	1.7	39.	4	3.4
19.	2	1.7	40.	2	1.7
20.	2	1.7	41.	2	1.7
21.	2	1.7	42.	3	2.5

Missing Values: Social Support Scale Short R					
Item No	Count	%	Item No	Count	%
1.	8	6.7	4.	7	5.9
2.	7	5.9	5.	8	6.7
3.	7	5.9	6.	7	5.9

Missing Values: Family Crisis Orientated Personal Evaluation Scales					
Item No	Count	%	Item No	Count	%
1.	5	2.9	16.	5	2.9
2.	5	2.9	17.	5	2.9
3.	5	2.9	18.	5	2.9
4.	5	2.9	19.	5	2.9
5.	5	2.9	20.	5	2.9
6.	7	4.1	21.	5	2.9
7.	6	3.5	22.	5	2.9
8.	5	2.9	23.	5	2.9
9.	5	2.9	24.	5	2.9
10.	5	2.9	25.	5	2.9
11.	5	2.9	26.	6	3.5
12.	5	2.9	27.	5	2.9
13.	5	2.9	28.	5	2.9
14.	5	2.9	29.	5	2.9
15.	5	2.9	30.	5	2.9

Missing Values: Family Environment Scale					
Item No	Count	%	Item No	Count	%
1.	2	2.8	46.	3	4.3
2.	3	4.3	47.	3	4.3
3.	4	5.7	48.	4	5.7
4.	2	2.8	49.	3	4.3
5.	3	4.3	50.	2	2.8
6.	3	4.3	51.	2	2.8
7.	3	4.3	52.	4	5.7
8.	2	2.8	53.	3	4.3
9.	2	2.8	54.	5	7.2
10.	2	2.8	55.	2	2.8
11.	3	4.3	56.	2	2.8
12.	3	4.3	57.	4	5.7
13.	3	4.3	58.	4	5.7
14.	2	2.8	59.	2	2.8
15.	3	4.3	60.	2	2.8
16.	2	2.8	61.	2	2.8
17.	3	4.3	62.	2	2.8

Missing Values: Family Environment Scale					
Item No	Count	%	Item No	Count	%
18.	2	2.8	63.	3	4.3
19.	5	7.2	64.	3	4.3
20.	5	7.2	65.	2	2.8
21.	3	4.3	66.	3	4.3
22.	3	4.3	67.	3	4.3
23.	2	2.8	68.	2	2.8
24.	3	4.3	69.	2	2.8
25.	2	2.8	70.	2	2.8
26.	2	2.8	71.	3	4.3
27.	2	2.8	72.	3	4.3
28.	3	4.3	73.	2	2.8
29.	2	2.8	74.	2	2.8
30.	2	2.8	75.	5	7.2
31.	3	4.3	76.	2	2.8
32.	3	4.3	77.	2	2.8
33.	2	2.8	78.	2	2.8
34.	2	2.8	79.	2	2.8
35.	3	4.3	80.	2	2.8
36.	3	4.3	81.	3	4.3
37.	2	2.8	82.	4	5.7
38.	4	5.7	83.	2	2.8
39.	2	2.8	84.	2	2.8
40.	2	2.8	85.	3	4.3
41.	4	5.7	86.	2	2.8
42.	3	4.3	87.	3	4.3
43.	2	2.8	88.	4	5.7
44.	2	2.8	89.	3	4.3
45.	4	5.7	90.	2	2.8

Children of Parents with Parkinson's Disease

A Research Report for the Parkinson's Disease Society

by Roger Grimshaw

NATIONAL CHILDREN'S BUREAU

The powerful voice of the child

Children of Parents with Parkinson's Disease

A Research Report for the Parkinson's Disease Society

Roger Grimshaw

May 1991

Updated, September 1991.

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Research projects concerning families require careful preparation and organisation, which cannot be achieved without a large measure of interest and cooperation from many different people. The Parkinson's Disease Society, which has made everything possible, deserves our warmest gratitude. A special tribute is due to those children and their parents who have participated so willingly in the research, giving access to many perceptive thoughts which have enriched the study. It is hoped that the report presents a reflection of their experience which can be distilled in forms useful for other families at the beginning of the Parkinson's experience.

I should also like to acknowledge the generous assistance of Dr Leslie Findley, Dr T.H.M. El-Debas, Dr Niall Quinn, and Professor Adrian Williams, as well as of Huw Meredith, Margaret Morgan, Alison McFadden, Richard Brown and Sophie Laws. Staff in the Welfare Department of the PDS have been always friendly and kind. Members of the YAPP&R network have also helped the research by their patience and cooperation. A particular debt of gratitude is owed to Margery Taylor, Mary Baker and Pauline Smith for their continuing interest and support.

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Roger Grimshaw

Contents

Introduction

The research project which began in mid-October 1988 came to an end in mid-January 1990. It has been conducted by Dr Roger Grimshaw, supervised by Dr David Berridge. Ms Philippa Russell has acted throughout as consultant to the project. Extensions to the project have been due to Roger Grimshaw's commitments at the Bureau which have been financed by the Bureau. These have been agreed with the Society. In addition the close of the research project has meant that work could begin on a new project to provide information about Parkinson's disease for children. This second project is now well under way and its progress will be discussed later in the report.

The main purpose of this report is to indicate the general progress of the research since its inception, though further details are to be found in the interim report submitted to the Society in February 1990. With the completion of the research, it is now possible to provide an account of the main findings. One qualification however needs to be made at this stage. This report does not represent a full description of the results; for this, project papers available from the Bureau must be consulted. It does, however, make an attempt to summarise and digest the main issues of the research and to point out their implications for the future.

The next step has been to report the main findings to those who kindly participated in the research. Given the delicacy of the research topic, we felt bound by an obligation to consult with families before final publication. After circulating the main findings, we now feel that no significant amendment is required to what remains a summary of the results. Our next task will be to discuss ways of publishing information from the research that may offer helpful suggestions for children, their parents and services in general.

General progress

The research project has, since our last report, been preoccupied with completing the collection of data and writing up the results. This has naturally left less room for the development of networks among interested people and for the increase of public awareness. However, now that the research data has been analysed, it becomes possible for publications to be produced which will address these broader aims. It is also now appropriate to consider some of the possible lessons of the research for services and for networks of self-help. Indeed this has been a major objective of the project. The work accomplished so far has already led to plans for producing information resources for children. It has, in addition, generated significant interest in further research concerning children of parents with a wider range of neurological disabilities. Before the research methods and findings are outlined, some more specific developments need to be mentioned.

It has been important to maintain links with initiatives for parents with disability, such as the National Childbirth Trust Register of Parents with Disabilities. As members of the Disability Working Group of the Maternity Alliance, we are looking forward to the conference to be organised by the Group in 1992. Some work during this research with the parent of a pre-school child will complement international links that have been made, notably with Megan Kirshbaum of the Through the Looking Glass project in California.

Attendance at various weekend seminars for YAPP&Rs proved to be a very useful preparation for the main research, as it gave opportunities for initial surveys and subsequently for participation in counselling sessions for families. It was also very pleasing that the son of a parent with PD has continued to work closely with the Bureau's initiatives on involving young people in services. Recently interviewed in the Bureau's national journal Concern, Michael Hanchett has participated in two of the Bureau's national symposiums. He has also taken part in the current work of the Carers' National Association, highlighting the needs and viewpoints of young carers in general. It has been fortunate also that the research has continued to attract interest from the Voluntary Council for Handicapped Children, an independently elected National Council established under the aegis of the National Children's Bureau and representing the major voluntary and professional bodies in the field of disability and children. It is hoped that the research described here will contribute to discussions about the situation of all parents with a disability. The national implications of the research were

emphasised when we were honoured by an opportunity to discuss the project personally with HRH Princess of Wales when she visited the Bureau in 1989. We therefore turn now to the progress of the research itself.

Research objectives

The initial review of existing knowledge suggested a number of issues which were summarised in the previous report and are reproduced here:

* Children's knowledge about the disease and their involvement in counselling and professional discussions; their understanding of what the future holds and its implications for their own lives.

* Children's life at home and any help they give within the home; the contribution of external services and support, in responding to children's needs.

* The care of infants and young children, and the advice given to adults with the disease who may wish to have children.

* The effects of these changes on children's relationships with parents, such as the 'role reversal' of providing care for adults, possibly of an intimate kind, and children's contribution to the emotional climate of the home, which may be affected by the changed relationship of adult partners.

* Possible consequences of the parent's condition for children's health, education, and employment; for their social and leisure activities; and the effects on friends, relatives and other important people in children's lives.

* Reasons behind the children's decision to leave the household, whether to carry on an independent life, or to undertake employment or education; the possible use of local authority care and other residential services.

* The planning of general patient care over the whole period of the disease and the extent to which the planning includes children at its different stages.

* The availability of services and whether children can successfully request them. These would include aids, appliances and adaptations; financial allowances, holidays and respite care which would be of direct benefit to children; and consideration of children's needs in service planning.

* The use of self-help and support networks as well as representative bodies catering for children themselves, including the work of the Parkinson's Disease Society.

It was explained in the previous report that several topics needed to be carefully explored before the research could be mounted. These included: the possible insights of child psychology in studying children's responses to information about health; more general ideas about parenting which might illuminate the notion of 'parental handicap'; and the specific range of impairments, disabilities and handicaps associated with PD. Better acquaintance with these areas of knowledge also made it possible to identify the inadequate scope of studies on similar topics (eg Arnaud, 1959; Peters and Esses, 1985). Specialist psychological approaches, we felt, lacked an appreciation of the range of social processes that needed to be understood.

In order to achieve a general perspective it was more useful in our view to study 'psycho-social' approaches, which asserted the importance of looking at the individual in the context of the whole family's adaptation to the crisis of illness (Thurman, 1985; Rolland, 1988). These mainly theoretical studies encouraged us to examine the styles of communication and the resources which families could draw on in coping with change. They laid emphasis on the stages of life through which families and individuals pass and on the need to understand how changes have particular impacts at particular stages in the lives of children and their parents. However extensive analysis has disclosed several issues which are inadequately treated by these studies.

The research design and its implementation

It had been planned to collect data in two forms: a sample of family case studies and an extensive survey of people in contact with the Parkinson's Disease Society. The importance of establishing the meaning of family experience led us to place great weight on the family case studies which more general survey findings might therefore complement. After taking advice, it was decided to approach younger people with PD through neurologists and through PDS in order to have access to a wider cross-section of people; both channels have contributed to the study sample. An account of the methods and results of both surveys and case studies will now be presented.

Developing the survey approach proceeded in two phases, the first of which was outlined in the previous report. Our work in the second phase produced methodological advances which we feel are significant for the future. In order to present a connected and comprehensive account the findings of the initial surveys will be rehearsed again.

Exploratory survey work

In order to understand more clearly the family circumstances of younger people with PD, it was decided to conduct a brief survey at each of the regional seminars for young people with PD, held in 1989. It was explained that our interest was in parents with children, so

this was a selective survey. There were in fact 45 responses (22 males and 23 females) from the total of 62 people with PD present at the three events. None of the people with PD chose to be classified as other than 'European' - a finding which was disappointing in terms of our wish to include a range of ethnic groups in the research. The average age of the sample was 49 years (range 36-69 years).

Analysis of their marital status showed 38 were married, four divorced, two separated and one widowed. Of the people who replied, 42 had children and the total number of children was 99. Analysis showed that there were 38 households with children aged 0-19 at the time of diagnosis. The average number of children aged 0-19 per household was 2.1. It was revealed that the ages of children at diagnosis were spread more evenly that might have been assumed.

Ages of children at diagnosis

Yrs	0-4	5-9	10-14	15-19	20+	All
	18	25	20	17	19	99

As the parents were on average aged 41 years at diagnosis, it can be concluded that a number had been building families in their thirties. Although it cannot be assumed that this is a representative sample, it is necessary to be cautious about any assumption that people with PD have finished with the major burdens of child-rearing.

At the time of the survey there were more people retired (6) or

permanently sick or disabled (20) than in work, either full-time (13) or part-time (3). If this were to be the general position several years after the diagnosis, then children's prospects of living in a household with reduced income should be appreciated. Indeed, taking only those currently retired or permanently sick or disabled, it emerged that there had been an average interval of nine years since diagnosis up to the present (range 3-14 years).

These results are not clear-cut since they do not tell us how long was the interval between diagnosis and finishing work. Oxtoby (1982) gives figures for a comprehensive age-sample of men which imply that 13 per cent were diagnosed before they were 45 years of age and 12 per cent finished work before they were 55 years. While our figures are thus suggestive rather than conclusive, they do help to indicate that it might be worthwhile to investigate the interval between diagnosis and finishing work. Though diagnosis may occur rather haphazardly in relation to onset, it might be useful to have some assessment of the prospects for parents when they receive a diagnosis. This may well be significant not only for them but for their families.

One additional feature of the sample deserves comment: only seven of the people who replied had as a main occupation a manual job. This result tends to confirm the impression of the Young People's Group as largely middle class, making it important for the research to include an adequate proportion of people from manual backgrounds.

Further survey development

The task of conducting a major survey of the YAPP&R group was made attractive by the good response to the initial research. But a number of obstacles stood in our path, as described in our previous report. Completing a full-scale survey of the YAPP&R group would have been very demanding, especially if partners and children, as well as people with PD, were to be included. It was our opinion that a survey of people with PD would be a realistic option but that expectations should not be set too high for a speedy completion of this task. In the event, a view was expressed by the Welfare Panel that a survey involving partners would still be extremely desirable. In order to accommodate this view as far as possible, it was agreed to develop a parallel questionnaire for partners and to pilot it alongside the version for people with PD. It would then be possible to reassess the practicability of a dual survey, even though this step would double the amount of data collected.

The potential benefits of such an approach were, however, enhanced when we learned about the joint research initiative of the Economic and Social Research Council and the Joseph Rowntree Foundation concerning 'personal welfare management'. A questionnaire approach along these lines would have been a useful preparation for a further project on a wider range of disabilities in parents, carried out under the terms of this research initiative. Confidence in pursuing the method was encouraged by the shortlisting of our initial application under the initiative. Although it was eventually unsuccessful, as often happens with a limited pool of funds, the

work on the application led to an extensive and comprehensive development of both questionnaires. Given the complexity of the research objectives, it was felt necessary to cover not only the parents' health, circumstances, and perceptions of parenting but also assessments of each individual child's experiences in various areas such as education, behaviour and leisure. These questions were also refined in order to give attention to children of specific age groups. In order to facilitate responses, questions were substantially pre-coded and matched, where possible, with existing survey data. The resulting survey instruments were therefore extremely thorough, the basic questionnaire for parents comprising 82 questions. A pilot exercise with the draft questionnaires was undertaken with the help of members of the YAPP&R group. The returns were sufficiently numerous to make it seem possible to proceed with the main survey.

However, distribution of the questionnaires within a reasonable time scale proved to be impossible. We were grateful to the editor of the YAPP&R magazine who had agreed informally to distribute the questionnaires. However, over the summer, we learned that the administration of the YAPP&R magazine was in a process of transition and it appeared that distribution of the questionnaires could not take place for some time and not before the September mailing of the magazine. Later enquiries, however, unfortunately revealed that there would be practical difficulties in distributing the questionnaires until the next YAPP&R mailing in December. The expansion of the mailing list also presented us with a substantially enlarged task of

administration. We fully accept the reasons for these difficulties and we are grateful for the hard work of all those connected with the magazine.

Nonetheless, we regretfully informed the Society last October that in our judgment the survey could not reasonably take place. While this outcome was disappointing and somewhat frustrating, we do not wish to underestimate the advances that have been achieved in developing methods of research. We feel strongly that these should not be wasted and look forward to a suitable opportunity to apply them. While the concrete results of survey work therefore remained exploratory rather than definitive, we feel that sufficient experience have been gained to provide a promising basis for further work in this hitherto underdeveloped area.

The development of the case studies

The outcome of the survey work therefore did not fully match our ambitions; however, the outcome of the family case studies certainly did. Here we were able to use the remaining time to best advantage. The previous report outlined how the case studies were selected. The sampling of families took place initially among members of the self-help group organised by the PDS, especially those families with young people. It was intended to examine families with perhaps better access to services than many, and to learn more from young people who had a long experience of contact with parents known to have the disease. The subsequent section of this report dealing with young people should therefore be seen in that context; the 'self-help

group' families were predominant in that part of the study. It can be suggested therefore that the actual outcomes for many of these young people, given their situation, may have been more favourable than for others (Pilling, 1990).

It was in order to contact a wider group of families that cases were also sought through helpful neurologists. Families not in contact with the PDS the were thus brought into the study. In addition, younger children were found and it is this group that is more clearly represented in the section dealing with pre-adolescent children. Studying the responses of younger children had required an extensive preparation of special interview schedules designed to take account of children's level of competence and to deal sensitively with situations in which PD was little understood. Methods of studying children under the age of five were also devised using the resources of the Early Childhood Unit at the National Children's Bureau.

Considerable attention was given to developing ethical guidelines for the study, as attached to the previous report. Subsequent to the research, some family contacts with services have been facilitated by the researcher, as previously foreseen.

The main qualitative research data has been in the form of semi-structured interviews, usually undertaken in the home, with 20 children and 20 adults, in a total of ten families. These were intensive and detailed, generating some 818 pages of transcript.

Details about these families are introduced in the separate sections concerning the two main age groups in the study - pre-adolescent children of school age, and young people. A special case study of a parent with a pre-school child is also being undertaken.

None of the people with Parkinson's belonged to minority ethnic groups, despite several attempts to contact individuals with this background. Efforts to obtain cases through the minority ethnic press, neurologists, and a special health-related unit for such groups were all unsuccessful. It is suggested that such groups may not be receiving appropriate health care that would make them readily accessible to these research approaches. If so, there are serious implications for equal opportunities in health care and related services.

In general, it will become clear that the sample contained families where the parents differed in occupation, in material circumstances and in progression of the disease. Children also varied in age as well as gender. It was to be expected that uniform results would not emerge and, where common trends were observable, these have been highlighted. At the same time, individual instances have also been mentioned where they give an insight into aspects of family existence.

A digest of case study findings

Instead of quantitative findings, we are interested here in qualitative description. The results of a qualitative study of families do not permit generalisations about outcomes for a wider population. Attempts were, however, made to obtain cases with a mixture of characteristics, such as the age and gender of children, and whether or not families were in contact with the PDS. Typically, qualitative studies seek insight into the processes by which children and their parents respond to change and evolve new ways of living. This emphasis on understanding process rather than on measuring outcome is essential in order to interpret research findings and to draw out their implications (Yin, 1989).

It is also important to concentrate not on finding evidence of adversities undergone by children but on showing how their perceptions and experience display a range of issues which have been encountered, some successfully, others less so. Rendering this texture of experience can make the study informative for those starting out with the disease and for those who may advise them. The approach is consistent with that envisaged in the original research proposal of the National Children's Bureau.

People with Parkinson's, like many people with disabilities, appeared reluctant to allow the disease to reduce their participation in normal activities. Being a parent was not a role that they seemed willing to forego without considerable effort. The effects of the disease were unlikely to eliminate many of their activities as

parents, though increasing disability brought with it physical and psychological changes that needed to be taken into account. Some of these could be overcome, though, in the extreme case, they posed marked difficulties not merely for activity but for communication with children. The role of partners in dealing with such delicate issues was an important one.

The social embarrassment associated with the disease was a common experience. Attempts to control the disease were often concerned with the management of appearances. Partners tended to share this intimate awareness of difficulties that people with PD otherwise sought to mask. Young people, in particular, grew in awareness of the various impacts of disability upon their parents. Difficult feelings had sometimes been caused when learning about the diagnosis but awareness of the progressive nature of the disease brought feelings of uncertainty about the future and led to some misconceptions.

Discussion about the disease was widely described as piecemeal and informal. Some parents with the disease did not engage in discussion or the task was left to partners. One problem for some parents and their partners was an awareness of gaps in their own knowledge. Misinformation from outside the family could also pose problems. Help in discussing the disease with children was generally not reported to have been received.

Younger children aged from five to 12 had been provided with very limited information about the disease and seemed reluctant to discuss it with friends. It can be argued that parents sustained a

sense of normality in family existence by their continuance of parental activity. Children's general ideas about illness were found to be concerned with certain themes, such as infection. They became aware of differences in their parents' general appearance but their ideas about illness did not actually correspond with their observations of the parents. Their situation can be described as one of 'protected uncertainty'. Where the parent's circumstances led to constraints on the children, this could cause strain in the relationship. Though some wished to know more about the disease, others were reluctant.

The material circumstances of families were affected by Parkinson's when disability led to the cessation of employment. Adjustments in the employment of partners were also required in some cases. Arrangements made to deal with domestic work highlighted the different contributions expected of men and women; there were also implications in these arrangements for children's domestic roles. There seemed to be an absence of systematic information given to families about help available. Though families received varying amounts of help from different sources, the contribution of children remained significant.

Help given by children to parents was often routine and incidental to the process of family existence. It was rarely discussed in families. Help that included personal care tasks seemed to be given more by female children, though children in the same family were involved to different degrees. Parents were reluctant to become a burden. However, at its extreme, caring by children could alter the

relationship with the parent in very significant ways. These matters led to little discussion with, or action by, services.

Processes of mutual understanding between parents and children were not generally felt to have been affected adversely, though some problems were identified. It was important, however, to recognise that families might go through a range of adverse experiences, of which Parkinson's was only one.

Parenthood also involves promoting and sustaining children's independence including their future beyond the present household. Children's attitudes to their health were not seen by parents as having been affected by PD, though children's own health experiences were significant topics. In the important sphere of education, most of the children and parents did not report substantial difficulties which could be connected with the disease. Friendships were also frequently said to have been unaffected, though embarrassment at the effects of the disease was a significant experience for young people. Young people's futures were not thought to have been altered by considerations about the parents' health. However, continuities of relationship were still important.

Though some young people would have welcomed counselling, this was not a widespread opinion and, in general, contact with other young people was not looked upon favourably. Contact between families and the PDS varied but the YAPP&R network seemed to be favourably regarded by those who were aware of it. But some parents did identify other needs, among them, one for counselling.

Younger children's perspectives

Living with someone who has a chronic illness may be a profoundly different experience from that undergone by most children (Kew, 1975). In a society for which health and disability have become increasingly open concerns, and where 'care in the community' has become an accepted slogan, the relationship between children of all ages and adult disease cannot be ignored (Farquhar, 1990).

A semi-structured interview schedule was used to focus children's attention on a series of key issues: their understanding of the disease, their ideas about health and illness, their perceptions of their parents in physical and emotional terms; their perceptions of parenting activity; and the daily routine at home and in school (Tamivaara and Enright, 1986). Since it was intended to examine broad themes rather than conduct a definitive survey, the seven children interviewed in depth (from four families) were sufficient to form a useful sample.

None of the four families were members of the Parkinson's Disease Society or its group for young people. This should be borne in mind in considering the findings. The adults with Parkinson's ranged in age from 35 to 45 years and, on average, had been diagnosed five years previously, through this period ranged from about one to nine years. The group had representation from both sexes, and each of the parents had a regular partner.

The parents had experience of several forms of impairment, each having a tremor, and most had experience of depression and tiredness. Speech difficulties were also encountered by two of the four parents. There were rather fewer disabilities, with writing the most common problem. Mobility problems tended to be subtle rather than obvious, with difficulties of balance and gait in evidence. Again, problems of handicap in such matters as employment and household work were not as frequent as the impairments stated above. One parent with Parkinson's was not working owing to disability but the others were generally working full-time. Similarly, most of their partners were either in part- or full-time employment. In terms of the scale of problems associated with the disease, the parents appeared to be at a mild or moderate stage (Hoehn and Yahr, 1967).

Their younger children were four boys and three girls, ranging from five to 12 years of age. Two of the four families contained older brothers or sisters. In a preliminary questionnaire, most of the parents indicated that they had talked about the disease with their children. Two indicated that they had no difficulty at all in this, though others showed some concern, for example, about discussing the idea of their children having the disease. None had received any help in talking about the disease with their children.

Children and Parkinson's - seen but not understood

In the four families where there were pre-adolescent children, explanations of Parkinson's disease (PD) had been, in effect, rudimentary or non-existent. Most of the children, but by no means all, understood that the tremor - the most obvious of symptoms - was due to an illness,

although one did not recognise it as Parkinson's. Only one of the parents with PD was acknowledged to have offered an explanation. Instead explanations of the symptom had come from a partner or a neighbour. Other symptoms such as rigidity and difficulty of movement had not been linked with an illness to any evident degree, though in one case a possible link was indicated. The effect of Parkinson's on a person's inner feelings had not been established in these children's minds. Children had generally not been made aware of the organic nature of the disease, its progression or the possibility of its being incurable. Nor were the treatments generally well understood.

If we turn from explanations to observations, a rather different picture emerges. All the pre-adolescent children said they had observed the tremor and all but one - the youngest - said they had noticed at least some difficulty of movement. It was also apparent that some children had become aware of some specific feelings and states of mind in the affected parent such as sadness or anger. Observations of some difficulty in ordinary bodily activity were made by several of the group.

Instances of tiredness were cited by nearly all the children, connected with 'illness' or 'headache'. Occasions when the parent showed great energy were less frequently mentioned. In two instances it was clear that children saw their parents as occasionally lazy or uninterested. Without adequate explanation, it is understandable that such a perception can be maintained.

Talking about illness

Children's ideas about the source of illnesses in general were directly investigated in order to find out what 'baseline' knowledge they might use to make sense of their particular experiences. One important idea was of infection. A link between this idea and Parkinson's was made by one child who wanted to know how his father had caught the disease. An association with infection had been explicitly created by one parent who had used it as a form of explanation for his illness.

Another central idea in children's thinking was the importance of good habits. Some children, in general discussions of diseases, referred to cancer and AIDS; such diseases might also have moral connotations, connected with 'dirty needles' (ie drug abuse). Knowledge of these diseases could also influence reaction to Parkinson's disease. One child on first hearing his parent had a disease had asked if it was AIDS, only to be reassured by the partner of the parent with PD.

A further idea which may be available to younger children is the notion of inherited disease, but little evidence of it was found. However, the idea of children as sufferers from a disease did enter into a few interviews. One child, asked what the disease might be, appeared to fix attention on what the sound 'sons' in the word 'Parkinson's' implied.

Child It's a disease for people that are going to have babies like that, I think so.

It became evident that there was some discrepancy between what children had been told and what they observed. Above all, there was a veil of mystery over any discussion of the parent's condition, which the parent

did little or nothing to remove. A similar rule of silence was influential upon the children's own conversations. There was no evidence that children in the same family engaged in discussion with one another about the parent's illness. Silence was extended to conversations with friends. Other children might be told but trusted to keep silent.

Sustaining normality

Family life and parenting are not straightforwardly affected by disease and disability. Children showed an awareness of parents' normal activities such as going to work, shopping and cleaning. It can be argued that such visible activities may be important in confirming the children's sense of parents' normality as active household members. Parents' leisure activity was also frequently mentioned.

Questions were asked about the parents' expressions of how special the child was to them, about parental prohibitions and about praise given to children. Generally both parents were identified by children as having a close personal involvement with them and if anything, those with Parkinson's were more easily associated with expressions of individual care. In the case where there were the fewest positive responses, it appeared that some pressures arising from a difficult domestic situation may have affected relations with both parents. Asked to recall a particularly sad occasion, they did not on the whole refer to Parkinson's, though one girl said her parent was sad because of his shaking arm. Occasions when the parent had felt loving were identified by many of the children. Anger too was an emotion which children could give examples of. Some of these, predictably, were to do with naughtiness but one spoke

about a parent's anger if the child did not help in the household.

Children's responses generally indicated that both parents showed some participation in developing their competence. Generally, the children said that their parents with Parkinson's had talked about the children's major school interest or about problems experienced in school. There was in fact no evidence to suggest that the children's room to play was affected adversely. A pattern of constraints on play and friendships was indicated in only one case where it was perceived that the parent wanted to be on her own when she was 'bad'.

Alterations to daily routines were not generally sufficient to require a major overhaul of children's ideas of what was normal. Assistance was given to both partners but, in a number of cases, slightly more accounts of help to parents with Parkinson's were forthcoming than of help to partners without the disease. It seemed that help to parents was readily accepted as the norm in less affluent families. One girl, for example, made breakfast, usually made the tea and sometimes washed-up. A number of difficulties in the relationship between the girl and the mother were also revealed by the interview. Constraints on the children's freedom were produced by the parent's emotional state. It needs to be pointed out that the partner in this family was obliged to work extremely long hours in order to maintain the household. For children placed in a family situation of this type, the consequences can lead to strain which may not always be resolvable. By looking at a case showing various difficulties, it is possible to put other, more comforting, findings in context.

It is possible that, when a parent's illness is represented to children explicitly, their repertoire of illness knowledge is mobilised in ways that call upon the imagination. Unless this impulse towards knowledge is addressed by the provision of appropriate information, there is a considerable scope for imaginative work which brings in a varied stock of ideas. Ideas about infection, contamination, bad habits, and terminal disease are current among children. The immediate question for them then becomes how their parent's condition relates to this set of ideas, some of which are frightening, others challenging to a parent's 'moral' status. Where disease itself is not regarded as responsible for what children see, ordinary explanations will be called upon which are not necessarily flattering.

If the imagination is stimulated by discrepancies, it can also be satisfied by maintaining a good semblance of normality. We saw several ways in which normality, and active parenting in particular, were maintained. Continuing these ordinary activities, managing appearances where necessary, enables parents to reduce the scope for damaging speculation. Indeed, if adults are seen to receive care and attention, there is no reason in a child's eyes for regarding this as undesirable. It is more appropriate for children to conclude that such people are the holders of a privileged and possibly enviable position (Kirshbaum, 1988). It is important to emphasise how much society expects parents and children to relate to one another in active ways. Children's active relationships with parents who had Parkinson's were thus sustainable in large measure but were not invulnerable to strain.

It is clear that children's ordinary resources of understanding are likely to 'put them off the scent', since aspects of the disease do not fit the standard profile of family illness available to children. However the evidence of the interviews does not imply that the parents' characteristics go unnoticed. Rather, the limited concepts available to children reduce understanding of those features of the illness which are manifest to them. Thus a potential gap exists between their understanding and the realities of chronic illness. Family life tends to conceal and shore up this gap. What must be recognised is the absence of information strategies capable of bridging the gap or reducing the impact of its collapse. 'Protected uncertainty' can, it appears, be sustained successfully but it may be a fragile structure.

All this is very different from assuming that there is naturally some latent urge in children to discuss issues and to find out more. The children held mixed opinions about whether they wanted to learn more about Parkinson's. Children who expressed an interest in further knowledge were also the ones who already knew that the illness was connected with the brain. These indications remind us of the importance of choice for children. While not every child will actively want to explore the ramifications of disease, it is essential to think about ways of allowing them to make that choice. Given the circumstances and approach of adults, it was not clear that these children had such a choice.

It is not clear that there exist fundamental obstacles to children's understanding if they are given the opportunity to talk in appropriate ways about those aspects which interest them. Talking with adults is a

social process. Children learn through paying attention to the ways in which topics are discussed. This can be called the social context of development (Light, 1986). Children's competence may be more a question of how they are engaged in discussions and how they are encouraged to see the 'point' of a particular statement. In considering 'what to tell' children about a disease, the issue may have more to do with <u>how</u> we talk with them than with <u>what</u> we say. If children are given the repeated opportunity to talk with adults about any aspect of a disease, there may be few limits to their understanding.

The perspectives of young people

The current attention given to young people who provide care for their parents has produced an interesting reversal of the 'generation gap' problem. Far from rebelling, young people became targets of concern and interest for the opposite reason: their devotion to dependent parents.

For some adults the attitude of young carers is entirely laudable. But a very different view can be found among those who are concerned about the opportunities for personal development which young people may forego as a consequence of their care and support (Fallon, 1990). At the same time it is argued that the extent of caring by young people reflects the failure of over-stretched services to supply the necessary care.

The relevance of these arguments to the general situation of young people with chronically ill parents is not straightforward. Not all parents become dependent. Not all have only their children to turn to for help. Not all fall outside the network of services. However, the fundamental issues which the debate raises affect, in one form or another, all such families. They pose the problem of managing a transition into independence and adulthood at a time when the parents' condition creates a possible obstacle to this process. Perhaps, above all, the debate spotlights the family as a social institution responsible for the care of its members. Chronic illness in a parent puts a question mark on the

transitions expected of both young people and their parents. While young people are drawn into closer involvement with their families, parents are faced with questions about their own capacity to promote or sustain young people's independence.

Young people's viewpoints were discovered by the use of a semi-structured interview schedule which dealt with major questions: their participation in discussions about the disease within the family or elsewhere; daily routines; young people's contributions to household activity and the care of the parent with the disease; their personal relationships with that parent; any consequences for the young person's health, education or career choices; possible consequences for friendships and leisure activities; young people's futures; and their contact with services and with networks of self-help. Most of the young people belonged to families in touch with the Parkinson's Disease Society's group for younger people with the disease.

The eight adults in this category with Parkinson's had an average age of 48, the youngest being 38 years old. Most were between 40 and 50 years old, though the oldest was of pensionable age. On average, diagnosis of the disease had taken place seven and half years previously, though that period varied from one to 13 years. There were three females and five males, each with a regular partner.

The parents had experience of various forms of impairment associated with Parkinson's, some physical but others psychological, such as depression, confusion and anger. The prevalence of disability was varied,

some having difficulty with mobility while others lacked only hand dexterity. Experience of handicap was also varied: some found it difficult to perform normal work or undertake social activities with children while others saw their activities as virtually unimpeded. Extensive disability and handicap were associated with no longer being employed.

Half of the parents with Parkinson's had ceased their employment, while the rest were in full or part-time employment. On the other hand, half of their partners were employed full-time while the others were in part-time employment, unemployed or looking after a home. Each of those who had ceased employment had partners who were in employment, usually full-time. The main occupations of the adults with Parkinson's included building work and child care as well as lecturing and management. The general characteristics of couples were therefore significantly diverse.

The young people consisted of five females and eight males, drawn from the eight families. Their average age was 20, the youngest being 16 and the oldest 24 years of age. Six of the families contained other children not included here; in three such families, other, younger children also participated in the study.

Learning about Parkinson's

Early awareness of Parkinson's impact on the parent was very difficult for most children to recall exactly. This may have been due to the creeping progression of the disease, and to a delay in informing the children. Most of the young people had first seen the parents' health problems when they were between 10 and 18 years of age.

At the beginning, while the disease was slowly advancing, physical changes in the parent were ambiguous. The emotional impact of realising the nature of the disease was in several cases significant. Worry about the future emerged as an important aspect of these feelings. Strong emotions such as panic and shock were also described in a few cases. For some, however, negative emotions were said not to have been experienced.

Children's access to information about the disease seemed to be a crucial influence. In general, it emerged that the participation of the parent with PD in talking about the disease formed an important contribution to the flow of information. In cases where only one partner talked about the disease, there seemed to be difficulties in broaching the topic and uncomfortable feelings were left unresolved. In one case, information had come solely from a neighbour and the young person said that no discussion took place in the family. Engagement in discussions, while not a panacea, seemed to open up some possibilities for addressing issues. However, children's information sources were largely limited by what parents could provide, which might be neglible. Without an independent channel of information, children were reliant on what parents could offer, some of it extremely meagre.

Some of the young people belonged to families in which the person with PD had an expert knowledge of the disease. Young people with access to sophisticated accounts of Parkinson's effects were able to discern a great deal about their parents' day-to-day behaviour. But this knowledge - sometimes almost because of its sophistication and complexity - did not exclude them from experiencing uncertainty, insecurity or error.

The impact of PD on a parent's health and physical capability can take a number of forms and will vary from individual to individual. Those young people who were asked for detailed accounts of their parents' health were usually able to give a discriminating picture not only of apparent symptoms but of the reasons for the problems they observed. Thus young people could see how activities became more difficult despite the fact that they were accomplished. There was awareness of variations in the parents' health and of the part which drugs played in governing the parents' levels of activity. At the same time the adults' inner states were regarded as observable - 'thought block', tiredness, loss of temper, impatience and so on - and these could be linked to health problems.

It was evident that the idea of disease as contagious is a significant one for young people. The notion of a 'contagious disease' has an ominous ring to it. The prospect of a very difficult future was an important part of young people's awareness of the disease. Visions of parents unable to walk, turned into 'cabbages' or prematurely senile were conjured up. How to envisage the future is known to be a difficulty for people with progressive conditions. For children the uncertainty may be less overt and pressing but nonetheless present in some form. Without clear information a young person who knows about the progressive nature of the disease can be left with only areas of speculation. The assumption that the disease would shorten the parent's life was found in more than one case, not necessarily among the least-informed. The word 'terminal' proved to be a slippery one, most marked in a statement that the disease was 'terminal' but nevertheless the parent would not die because of it.

Providing help

It was clear that some participation in maintaining the household was regarded as a normal feature of young people's lives, whether concerned with housework, errands, shopping or looking after siblings. Regular activities of this kind could be regarded as part of a reconstructed domestic routine, especially if a partner was unable to give the attention required. Routines of family existence were not generally affected by Parkinson's disease. Help was usually more incidental and diffuse, concerned with small items of assistance that flowed easily into the day.

A significant question was whether young women or young men helped differently. General help was, in some degree, given by some young people of each gender. However, participation by young males was not universal, and gender played a part in the extension of routine help to embrace the needs of the parent with PD. Here it appeared that young women were drawn into the process of caring in a more direct sense than their male counterparts.

Young person. ...The daughter tends to be the one that helps, more so than probably (my brother) did.

In general, help given by young people to parents with PD included forms of personal care, especially in dressing, and extended to help with feeding, using the toilet, increasing mobility, and lifting the parent. Examining patterns of help among children in the same family, it also appeared that there were differences among the various children in the scope of help which they provided.

It was necessary to look at children's help in the context of the various sources of other help that may have been available. There was a strong impression that, whatever the provision of other help, children's assistance was a significant part of family existence. In addition it was of considerable subjective importance for family members.

It was hard to identify anything resembling family discusssion of the help provided by young people. If anything, assistance was underpinned by a code of silence. Children also had learned to be tactful in recognising the limits that parents wished to place on the help which was given.

However, there were instances where the relationship altered and the balancing of roles could not be preserved. One form of this change was a recognition by the young person of the parent's sexuality. This could occur when helping the parent to dress. One parent apparently recognised the problem and help with dressing was brought to an end. At its extreme, however, caring by young people took on a purely practical aspect and the personal relationship was relegated to second place. What kept the caring alive was the thread of family obligation.

Negotiating tasks within the household was not always straightforward. Partners could take a significant role in indicating what help was needed. However, the indirect ways in which these processes occurred could leave a burden on personal feelings. A sense of obligation was present in the young people which commonly made them feel their efforts were insufficient. The family became therefore a theatre for the expression of complex feelings rather than a site of discussion.

The privacy of the family in these situations was accepted by services. A crucial indication of its social acceptability was the lack of discussion between young people and services. A stark example of the problems caused by lack of discussion was a call for training to be given to young people in how to give practical care. The strength of the family's willingness to cope 'normally' was thus a powerful constraint on discussion with people outside the family, despite the strains that coping produced. By accepting the situation at face value, the services were perpetuating these strains.

Relationships and personal feelings

It was necessary to look at possible contrasts in the close personal relationships between the two parents and their offspring. Here there was generally little indication that the person with PD had become a secondary participant. However, a parent's dependence on children's help was reported to lead to indulgency towards their unacceptable behaviour. Or children were said to have taken advantage of a parent's inability to control their behaviour. There was little sign that the feelings of parents with the disease were less understood than their partners'. Nor was it evident that they showed less understanding of young people's feelings. Communication difficulties associated with the disease were, however, seen as hindrances to the continuance of close relationships. These included speech difficulties, marked talkativeness (a side-effect of drugs), and blank expressions.

While communication processes within families were often strong enough to enable parents to function, there were still complex issues of

emotional significance. Children's responses to the parent's situation could be sharply observant, involving feelings of both resentment and identification. One response was to identify the aggressiveness and impatience of the parent. An alternative response was one of total identification with the parent. For example, one young person had become the partner's confidant and supporter. When the partner heard about the diagnosis, she was 'heartbroken', according to the child. A similar reaction occurred simultaneously in the young person. But this case was also remarkable, not for the reactions of individuals, but for the intensity of the family's communal life and sense of mutual responsibility.

It was vital to recognise that Parkinson's was not the only aspect of family experience that could be seen as problematic. Young people talked about PD as part of a broader family experience which could have a negative dimension. Though some families had experienced periods of unhappiness for a variety of reasons, there was no straightforward pattern of unhappy times attributable in some way to Parkinson's.

Multiple health difficulties which had caused significant disruption or loss to the family were important topics sometimes fraught with emotion. Parkinson's became one aspect of a family experience in which a range of health problems had been experienced. Children's own health problems were also significant experiences that in some cases prompted reflections on the relationship between parents' and children's situations.

Developing themselves - education, careers and friendships

During the phase of youth, education assumes great importance and parents are often expected to promote their children's achievements. Most parents were said to have participated in such encouragement, by visiting the school, talking about the major school interest of their children, or about problems. Conversations at school, with teachers or schoolmates, about Parkinson's were limited or non-existent, confined to polite enquiries, or shared with close friends. If anything, such conversations were regarded as embarrassing. The only young person who claimed that Parkinson's had had a detrimental educational effect spoke of the difficulty of doing homework when she was helping at home.

A significant part of young people's development is also formed by leisure interests. A number of parents had talked about young people's major interest outside school, usually in a helpful way. Meeting friends is also an important part of growing up. However, there was no substantial evidence that young people encountered problems in seeing friends where they wished. One young person was, however, clearly aware of a difficulty which the current accomodation caused. Little change in the nature of the friendships was reported, though, where there were several difficulties in the relationship with parents, intimacy with friends increased. One difficulty in some cases was the problem of explaining the nature of the disease or dealing with friends'fears about it.

A number of children also spoke of their embarrassment in talking with friends. The onset of obvious symptoms coincided in one case with the beginning of puberty. Having a parent with Parkinson's became a social

embarrassment and produced fears that friends would be rejecting.

Young person. You think they are not going to want you because... they are going to feel embarrassed by this situation.

Talking with their children's friends was something that a number of parents did but some were said to do so rarely. However, it was not usual for friends to go out with the young person and the parent. While young people initially saw their parents as embarrassing, it was possible for these feelings to be overcome.

Looking backwards, looking forwards

It is important to recall that families and illnesses each have a history. Asked to compare their perceptions of the parent with the disease before and after its onset, young people tended to refer to physical changes. Asked to assess changes in their own feelings as they grew older, the young people generally spoke of greater understanding and knowledge, more acceptance and less discomfort, although worry was also mentioned. As well as a history, young people have a future to consider. Leaving home is considered a normal part of developing an independent status in society. Young people were generally clear that Parkinson's was not a factor in their thinking about leaving home. Some young people asserted an independent identity which reflected dissatisfaction with their parents' norms, separate from the problem of Parkinson's but certainly contemporary with it.

However, one young person said that he would stay at home if it was

necessary to provide care for the parent. Another spoke of not wanting to leave home and one emphasised how sensitive was the topic of the parent's future. In some cases, living in the household still retained attractions or spoke to the mutual concerns of parents and child. Looking forward did not necessarily mean a complete break, and continuities of relationship were clearly significant.

This does not always mean that the relationship exists on the same basis. While some attention to the dilemmas faced by such young people in negotiating their independence has recently emerged in the literature (Rolland, 1988), it is not yet clear that the consequences of these dilemmas have been fully grasped in particular cases, where caring responsibilities are onerous. The ground was prepared for the extension of young people's responsibilities if the parent's alternative resources in the family were diminished either by growing needs for care or by the unavailability of a partner. The solidarity of the family as a communal unit was a major fall-back resource for parents in stressful and deprived circumstances, even if that meant increasing calls upon children's aid. But that course could lead to a major reconstruction of relationships in which 'role-reversal' became a possibility. A young person would then defend the partner from what were seen as the demands of the parent with PD. A further step was for the young person to uphold the needs of a sibling, against the insistent calls of the parent with PD. Parkinson's then became only one claim on the family's diminished resources.

The apparent general attitude of external services to children's assistance could best be summarised as 'out of sight, therefore out of

mind'. Yet such attitudes took no account of the complex changes in relationship which could be produced and ignored the questions surrounding children's competence to provide care.

In examining the implications of young people's situation, their attitude to self-help networks and services must be taken into account. In general, few of the young people had experienced contact with other children of disabled parents or those specifically with PD. This was despite the membership of most parents in a self-help group organised by the Parkinson's Disease Society. A few had experienced contact with the Parkinson's Disease Society, usually by attending its meetings. A greater number had some knowledge of the YAPP&R magazine, to which attitudes were generally favourable. The attitudes of young people to contact with others in the same situation were not generally positive.

In general there was no great demand for counselling about family feelings but a small minority of young people would have welcomed some form of counselling, had it been available. It can be suggested that, unless the home situation is one that young people feel unable to influence, they are unlikely to want to go outside the family in exploring the realities of the disease. At the same time they are likely to want to have some influence over any service initiatives made in their name.

The perspectives of partners

One of the factors which sustained family existence was a commitment to carrying on as normal. Partners were likely to uphold this principle.

Partner. ...we just carry on, you know, like anybody else, as if he was normal, you know. We do.

'As normal' meant remaking and reasserting customary patterns, where at all possible. It was against this background that partners described what had happened, careful often to distinguish between adversities attributable to the disease and those that could be linked to other causes. The ten partners (six female, four male) were interviewed using a semi-structured schedule similar to that used for people with PD.

Communication with children about the disease had generally been piecemeal over time and informal in tone. Partners seemed to feel that their powers of explanation were reduced by a lack of medical knowledge. Reactions from children were reported in a number of cases to be muted, with little discussion resulting. However, in a few cases, children's sadness and grief became apparent; in one case the partner described how the child's underlying sadness was revealed much later. In other instances, it seemed to be assumed that children had taken the news in their stride. This was in contrast with the typical reactions of the two

adults which were often described in more definite and emotional terms. Children were therefore, in principle, seen as largely free from adverse reactions, having been supplied with information in small doses.

However, the process of piecemeal communication was vulnerable to a shock delivered from outside the family. One partner reported how her child had been upset when another pupil had said 'Your dad's going to end up in a wheelchair, isn't he?' Asked if this was true, the partner had replied that it was possible but not inevitable. It turned out that the parent of the pupil concerned was an acquaintance of the family and, having medical knowledge, had probably talked about the disease. Here, children's participation in a world of knowledge outside the family was a factor capable of disturbing a child's apparent acceptance of the situation. In addition a television programme about Parkinson's had produced a similar effect.

None of the partners said they had received any help in talking with their children about Parkinson's. To some, this presented no problem but others would have preferred to have had access to help, in the form of a special booklet, assistance from a GP or through contact with other people having disability.

Continuing in employment was a significant consideration for parents with PD. Uncertainties about the disease were a spur, for example, to constant work, anticipating the time when employment would have to be abandoned. For some, the consequences of disability had not been severe enough to threaten their employment. One person with PD was said indeed to

have moved to a better job after the diagnosis. In those cases where employment ceased, however, partners were likely to have faced important choices about their own employment. Extended hours of work represented one option, especially if financial resources were stretched. But this could cause problems in meeting both the needs of the person with PD and of the family in general. One partner had in fact taken two jobs in order to solve the family's financial problems, a situation acknowledged to be unsatisfactory. Hours of work were occasionally inconvenient and required adjustment to suit needs at home. Those partners who worked for long hours were also disadvantaged in supporting parents with PD in their dealings with services.

Nonetheless, family income was important. In some instances, a fall in family income had been experienced; in a difficult case, a partner was keen to obtain a better job, having felt guilt at an inability to provide adequately for the person with the disease. Parkinson's could also make extra demands on the family income, by leading to 'wear and tear' on household goods or additional medical expenses. Accommodation was another significant material factor. Accommodation problems affecting children had been experienced in a few cases; in one, these had to date proved insuperable. Clearly, material issues could assume great importance.

For partners, there was sometimes a very acute dilemma between the rewards of employment and the benefits of providing care to people with PD. Both options might increase the welfare of the family but neither could be pursued at the same time as the other. In one particular case the partner's full-time employment had been part of an arrangement in which a

young person adopted the role of main carer, but eventually difficulties led to a new arrangement in which the partner worked part-time. Here the trade-off between financial rewards and time spent at home had failed in ways that were felt to be detrimental to the young person concerned. This was a clear example of the potential pressures placed on young people by the conflicting demands on partners.

There were various degrees to which housework and child care were said to be distributed between the partners, depending partly on the level of disability, and partly on their respective employments. But gender also seemed to play some part. One mother with PD argued that disabled women were disadvantaged by their gender in that their household work would still be expected to continue. There was some indication that expectations on men were not onerous in this respect. One partner, for example, stated that her husband now retired had done little domestic work since the start of his illness. On the other hand, a male partner mildly complained that occasionally his wife did not perform her household duties while he was working. In another case, a partner, himself with especially heavy employment commitments, spoke of the reluctance of the person with PD to admit exhaustion, thus perpetuating her own burden. On the other hand, it was explained that their older children catered for themselves.

Self-reliance in children was, in fact, important to some partners in full-time employment. Since there would be occasions when the parent would not be able to do anything, it was crucial that the children should be taught to do as much as possible for themselves. This view was expressed by a male partner who had extensive employment commitments. Children's

self-reliance was therefore a value that made sense to partners whose conventional role in the household was as 'provider'. It should be added that 'do-it-yourself' jobs were seen by some women as significant household duties for men. Expectations related to gender were therefore influential.

Partners were capable of a special awareness of the problems experienced by the person with PD, both in private and in public, for example, the difficulty that PD could cause in managing appearances socially. With strangers, problems such as slowness could give rise to impatience. In the company of friends and acquaintances, jokes were employed to ease any self-consciousness. While the public face of Parkinson's had its problems, so did the private face. Partners had a privileged access to the private world of Parkinson's that has recently come increasingly to notice (Vaughan, 1986; Todes, 1990). The physical dimension of that private world was poignantly expressed by those partners who had intimate knowledge of difficulties such as bodily rigidity at night and the tedious interruptions of the 'off-state'.

The psychological dimension of Parkinson's was also described by partners who spoke about depression, frustration, weeping and loss of temper. Sharing the burdens of the Parkinsonian world also gave the partner access to those unhappy feelings about the disease that might not be so easily visible to an outsider.

The intimate awareness of partners about the condition was also combined with a leading role in the provision of support and personal

care, where necessary. Help from close relatives was acknowledged in a number of cases but was not a solution for everybody; in one especially trying instance, relatives' help was entirely absent. Friends were regarded more as sources of support than practical help. Unfortunately a deterioration in friendships was felt to be one possible result of the social disadvantages associated with the disease.

Some families received the help of a care attendant or home help and had installed special aids. Some employed domestic help. Others felt that outside help was not yet necessary. There seemed, however, to be no systematic process by which families learnt about help available. Much was left to the initiative of individuals or to personal contact with others in similar situations. Opinions about what further help was needed varied according to both the stage of disability and the current information available. Some partners expressed a wish for further help of various kinds, including better explanation of problems, contact with services and clearer advice. Even where outside help had been obtained, partners still identified outstanding needs, in particular for respite care. One partner, however, had obtained some respite care, arguing that her child needed more attention from her. However, partners could find their responsibilities a strain. Though health problems among partners were not inevitable, it became clear that some were conscious of strains that might lead to psychological difficulties (such as hopelessness) or to a physical problem (like high blood pressure).

Changes to children's daily routines were not generally identified but, as stated earlier, there was some emphasis on the need for them to be

independent in looking after their own needs. Various contributions by children to household work (and in some cases to the personal care of person with PD) were described by partners but, surprisingly, very little discussion of this help was reported, either within the family or with services. Just as the various ways in which partners juggled with their options and responsibilities were highly discretionary and invisible, so also were children's contributions.

Some alteration in the way the parent with PD related personally to the children was described in several cases by partners. One observation was of greater irritability in the parent with PD. Another was of tiredness, leading to reduced interaction. Partners might then become intermediaries, talking more with the children, 'protecting' them from contact with an irritable parent or trying to account for an instance of weeping. At a high level of physical disability, the parental role became markedly difficult. Loss of ability to talk and smile was a factor here and was observed in some form in a number of cases. More rarely, it was claimed that children's own behaviour made the parent's health worse. If personal relations were felt to be vulnerable in some respects, the children's self-development was not perceived negatively.

Fortunately there was little feeling that the disease made a difference to the children's attitudes to their own health. Some (but not all) partners thought that the parents with PD showed less energy and inclination to be outgoing in assisting the children's education. However, the only case where job choice was felt to be influenced was where a child was motivated towards financial security. The children's friendships were

generally seen as unaffected but substantial disability (as well as particular problems such as blank face and irritability) was occasionally felt to impede social mixing. Although problems with mobility were commonplace it was pointed out that these did not necessarily affect young people. Family holidays were not significantly affected except where the level of disability was perceived to be a daunting factor in planning a trip abroad. The encouragement of children's leisure interests was also broadly felt to have been unimpaired. Younger children growing up alongside a parent with the disease were seen as best able to cope. A very young child was said to copy the parent's shaking unselfconsciously! Older children were felt to be rather more vulnerable to stress or social embarrassment. There were few concerns about an adverse effect of PD on the children's futures. Nor was there any general sense of disappointment about parenthood attributable to the disease. In only one case there was a clear indication that Parkinson's had curtailed the couple's fertility. Indeed in a number of cases children had been conceived while the person had been affected by the disease. In this regard, it has been pointed out that very little specialist advice for couples is currently available.

Parents with Parkinson's disease

Parental perspectives were derived from interviews with ten adults (four females, six males). It will be necessary briefly to compare these accounts with what has been outlined previously. At the same time, it is appropriate to consider the special viewpoint of those with the disease. Perhaps, above all, their concern was to identify the signs of normality in family existence and in their children. The interest in maintaining normality was reflected in accounts of what children had been told about the disease.

A few parents indicated that information given to children had been minimal or non-existent. Others confirmed that any information about the disease had been communicated informally and led to little discussion with the children. Though some parents had a good knowledge of the disease, lack of knowledge could be a handicap. While some parents took initiatives to explain points and make information available, others had not seen this as appropriate. In one case, the curiosity of a child relative had been 'passed off'. In some cases the partner, not the parent, had talked with the children. While younger children might be seen as unaware of the disease or too young to understand, young people were reported to have posed few questions. Some were said to have been 'unimpressed' or to have made jokes. One spontaneous question emerging from several young people was said to have concerned inheritance of the disease. Parents' accounts

thus tended to emphasise the 'low-key' aspects of the communication process, perhaps even more than partners'. A need for specific help was identified in a few cases, involving a booklet or contact with other children in the same situation. However, another instance of misinformation was reported. A parent reported an incident where a fellow pupil had insisted to one of the children that PD was terminal, causing considerable distress.

Control over their material circumstances was also a significant concern. In a few cases parents described how they had tried at first to conceal their PD from work colleagues. It was clear that adjustments were sometimes necessary to patterns of work but some people were continuing much as before. But concerns about the future were nonetheless expressed. Several of the parents, however, had ceased or reduced their employment and in a few cases this led to guilt at the load placed upon partners. Inability to continue work was felt as a particular blow especially when it resulted in confinement in the home. The resulting drop in income led sometimes to hardship especially when the financial costs of disability began to appear. Expenditure on children's needs could form an additional call on stretched resources. Other families had not expressed this pressure. Accommodation difficulties were found to affect a minority of the sample, though their implications for children were significant.

Parents described how Parkinson's had initially affected them. The diagnosis tended to have been received negatively, as a shock. Lack of tact in disclosing the diagnosis was also a significant topic of complaint. Parents gave accounts of difficult health experiences which

went beyond the classical signs of Parkinson's, such as tremor. These included adverse reactions to medication, such as cramps, hallucinations, tension, bad temper, and volubility of speech. It is important to recognise that disease and treatment each make up the reality of the PD experience and contribute to its social manifestations. The chief subjective difficulty was embarrassment. Social embarrassment was a significant and problematic experience. As one put it, '...if everyone else around me was blind, then I could handle it'.

The variability of the disease posed a problem in suddenly revealing to outsiders what might otherwise be masked by treatment. One person described getting off a train before reaching the stop required, in order to avoid passengers' stares. Lack of confidence in social situations had been one result; communicating about the disease to strangers could be especially trying. In some cases parents felt a need to be accompanied which was in itself restricting. Slowness in movement and even in thought could also be disadvantageous in public places. Overcoming such feelings presented a particular challenge.

A further insight into the psychological reality of Parkinson's was given by parents who talked of unhappy states of mind, including depression, disinterest and hopelessness. Though not all had undergone such experiences, it was important for the research to explore those feelings that had been perceived by others in the family. Depression following the diagnosis could be exacerbated by other family adversities, including the responsibility of caring for young children.

In describing the help received by parents, it needs to be remembered that attitudes to it have crucial implications for understanding the social meanings of illness and disability. Where illness and disability are felt to be misunderstood and patronised, people with health problems face acute difficulties in receiving appropriate help. Where help is perceived to be unnecessary or unsuitable, it may therefore by rejected. Not feeling a need to call on help was an important part of maintaining normality for some people. Indeed refusing help was regarded as appropriate in more than one case precisely in order to avoid feelings of helplessness. Being fussed over was unlikely to be acceptable, as it suggested invalidity rather than disability. Accepting help was therefore a stage in itself, when it was necessary to 'put your pride in your pocket'. Perceptions of help need therefore to be set against the background of wishing to remain independent.

Help and support from relatives and friends were reported in a number of cases but sometimes this contribution was seen as disappointing. Supportive attitudes were a particular benefit given by friends. However it was surprising to learn that practical help might be penalised. One very helpful relative was apparently threatened with official repossession of her home because of the time she was spending with the parent.

Lack of systematic information about help available had been a commonplace experience. Not being told about sources of help posed a great difficulty, especially when the parent felt an isolated case. One GP, however, won exceptional praise for quality of advice. It was in this context that the families maintained their daily existence. Disturbances

to daily routine were normally seen as minimal. In general males tended to point out their lack of involvement in housework in ways that were not so clear-cut in women's descriptions of their own domestic arrangements. This difference may be due to norms about gender.

Descriptions of children's help generally corresponded with the accounts set out previously. One daughter was described as 'a second Mum'. Variations among the children in their level of help were also pointed out, though little family discussion was reported. But the idea that help from children should be minimal was also a significant theme. Despite these reservations, the level of need could make help from children unavoidable. So strong was the sense of family obligation in one family that the children were said to have rejected the possibility of outside help, wishing to do everything themselves. Problems in service provision were, however, identified by parents in cases where children's help had become the norm. In the instance mentioned the parent had spoken to a sympathetic hospital social worker who was said to have been 'horrified' by the amount of work expected of the children and, as a result, more home help had been provided.

A number of parents detailed the active ways in which they pursued a personal relationship with their children. However it was necessary to come to terms with the advantages and disadvantages of the situation. The value of time spent with children was enhanced by awareness of reduced opportunities for interaction with them. Having more time was seen as a compensation for ceasing employment but disability was a handicap in undertaking physical activity with children, especially outside the home.

In some families it was customary for females, in particular, to control the children, becoming 'irate' with them. Where this type of responsibility fell on a mother with PD, it seemed to be stressful. It was noticeable also that mothers of young children felt a particular strain from their children. Children's special needs were an additional call on parental energy and patience. If it was difficult to meet children's needs, this could be seen as a source of unhappiness. On the other hand, having a young child could be seen as a stimulus to cope with the disease.

Communication processes were said to have been affected in a number of cases. One aspect was the impact of speech difficulties, which could be frustrating. Another was a reduction in smiling. This blankness of expression was subject to an imaginative strategy. One parent had put up a poster with a picture of an impassive eagle, captioned 'I AM SMILING'! There was some tendency to qualify statements about mutual understanding between the parent and the children. One parent argued that children were loth to express their true feelings to their parents. However only one parent was relatively negative about mutual understanding and one thought that he understood his children's feelings better. None felt the children's attitudes to health had been adversely affected. Even the vicissitudes of illness and treatment - 'short-term shocks and surprises' - could be dealt with by taking initiatives, encouraging children to look at the problem calmly and objectively, becoming a source of fascination and interest.

Children's own areas of development were generally looked upon as not presenting insuperable problems. Two parents however had found

difficulties in supporting their children's education. A similar number referred to problems that may have affected children's friendships. Their leisure was also generally felt to have been helped. Though family holidays were not generally curtailed, one parent felt that others in the family needed a respite. In reflecting on age differences, there was a significant feeling that growing up with the disease from an early age was preferable. A younger child who had always known the person as someone with PD was felt to have accepted the situation more than another who had first encountered it when beginning school. However older children were not necessarily seen as responding poorly. In looking at their whole history, it was rare for parents to express any negative feelings about what had happened. A number of parents had conceived children around the time Parkinson's appeared; one mother had planned to have a baby in full knowledge of her diagnosis. Family fertility had not been curtailed by Parkinson's as such. It therefore seems that the family commitments of people with PD are unlikely to be reduced for this reason, though other difficulties did have an influence on decisions to bring child rearing to an end.

Finally, attitudes to group contacts were explored. Those who had experience of the self-help group were more positive about contact with other people having PD than those who had not. One strand of feeling was that PDS meetings had a dull and passive atmosphere - 'stick-in-the-muds', as one put it. Scones and raffle tickets summed up the impression of a similar group for older people. A more extreme position was the desire not to see a reflected mirror-image, thus projecting uncomfortably the person's own problems. A desire for avoidance here contrasted with the

benefits which a number of other parents had found from their contacts with the self-help group. However, not all felt that it was as helpful as might have been; needs for counselling and for education in disability were also expressed. One problem was having the energy to participate in group organisation.

Living with the disease can be summarised as a process of change in which there is a struggle to control problematic experiences and hold them back from others, especially children. Much can be done to achieve these aims but, as we have seen from other evidence, the nature of family existence means that some part of those changes impinges on children. Identifying the perceived consequences of such change has been an objective of this research, which may be useful in increasing awareness of what life with Parkinson's may entail. It needs to be recognised how people struggle to turn the extraordinary into the ordinary and how children's presence in the family can be an incentive to that normalisation. But at the same time children's participation in the family emphasises that they are not passive or unaware, but active contributors capable of showing mutual feelings and developing their own potential.

Implications of the study for services and networks of self-help

The points covered by this study obviously cannot provide definitive guidance to those concerned with children and young people. However, it is possible to formulate certain principles which are related to key aspects of their situation. Those principles require further discussion with children and their parents but, with the benefit of appropriate modifications, they may serve as guidelines for the development of policy and practice among services and self-help networks.

* From the evidence of exploratory surveys, it should not be assumed that younger people with PD have ended their major responsibilities for bringing up children, including those in early childhood. Coping with parenthood is likely to be a significant issue for those in their 40's and 50's, as well as in their 20's and 30's. The formation of second families can also occur at a considerable age.

* Parkinson's itself is not likely to be seen as an absolute bar to having further children; specialist advice for couples appears, however, to possess some limitations.

* Children have a right to a suitable explanation when a chronic illness in a parent impinges on their normal way of life.

* They have a right to an explanation which relieves them of

responsibility for those changes which are due to parental illness.

* Children should normally have a choice about when they receive information and how much they wish to receive. This principle should not preclude a change of mind; indeed a change of mind is consistent with the principle.

* They should be allowed to talk about topics that interest and concern them in a form with which they are comfortable.

* Their existing knowledge of disease and disability should be taken into account, as well as the ideas current in society.

* Explanations should include not only facts about a disease but the reasons behind changes in the pattern of parenting or household routine.

* Children's access to information is dependent on the access of parents and this is likely to be variable. Information designed for children themselves may be of assistance both to them and their parents.

* Children's conceptions of disease are rooted in a common-sense knowledge of illness which leaves room for uncertainties and errors. Discussion within the family is a potential instrument for clarifying their understanding and knowledge. Services have a responsibility to make information and counselling available to those who request it.

* Children's contributions to maintaining the household and providing care tend not to be openly discussed within the family or with services, despite their significance and the burden they impose in a proportion of cases. Children and their parents may benefit from encouragement to discuss how the help fits within their developing relationship.

* When children are asked to help their parents, they should be given an explanation which accounts for the role and consequences of parental illness. Where help is given by children, this should be openly regarded as part of a fair and reciprocal relationship, and not as a simple duty.

* Services have a responsibility to make clear the level and types of help they can provide to families, taking into full account the potential demands on young people and the consequences of those demands for their welfare. Services, in addition, should be obliged to ensure that young people are consulted about decisions concerning help which may affect them. The personal development of young people having a parent with Parkinson's disease is influenced by a range of experiences and the disease may not be the only adverse element that they may confront. Services which become concerned with children's personal development should ensure they are capable of identifying those various difficulties.

* The progress of children and young people towards autonomy and independence is influenced by their capacity to develop freely, in the

spheres of leisure, education, friendship, work and so on. Those who have responsibilities towards children will need to consider the possibility of constraints on their freedom to develop, especially in the case of individuals who, for example, provide significant assistance or lack appropriate accommodation. The impact of these considerations for young women and young men needs to be carefully assessed.

* Social embarrassment associated with the disease represents a problem for adolescents, in particular, and communication strategies which address this difficulty should be encouraged. The promotion of positive images of disability could make a wide contribution here.

* Young people's futures need to be considered as part of a complex transition towards autonomy and independence in which young people's ties of feeling and obligation to parents remain significant.

* Service initiatives designed to meet young people's needs must present clear objectives that address young people's aspirations to influence and control their personal futures.

* It is for society as a whole to look again at its responsibilities to all young people and their parents in order that a transition to independence can be made with genuine dignity.

Reports and publications

It has been part of our research strategy to define as carefully as possible the objectives of our publications. These have been designed to be of interest to particular audiences. An example of this approach has been described already, in the preparation of a paper for a sociological audience on 'psycho-social' approaches to children of parents with complex disabilities.

A presentation about the research project had also been given in March 1990 to a seminar organised in Glasgow by the National Children's Bureau Scottish Group, attracting a wide-ranging audience of delegates. Subsequently an article has been published in the Group's journal Scottish Concern. It is also hoped that the current report, together with the more detailed descriptions and quotations contained in project papers, will create the basis for a publication intended to increase practitioners' awareness of children. At the same time, such a publication would be of interest to those families coming to terms with a diagnosis of Parkinson's.

Another crucial audience consists of children themselves. Plans to produce an information booklet were described in the previous report. These have progressed well, thanks to generous donations totalling £11,500 from the BBC Children in Need appeal and ITV Telethon. Work has already begun on a draft booklet and it has been piloted with families not in touch with the PDS. Further discussion is now taking place with the Society about a range of possible information resources for children and young people. It is hoped that these resources will also help to promote

the work of the PDS.

So far, the costs of development have been met from the sums donated by the two appeal funds. An amount has also been set aside for production of approximately 2,500 booklets. The eventual costs of producing the information resources remain to be determined and we would welcome discussion about whether or not further special funding is likely to be required.

Another element in plans to produce information for children has been to commission a video. Now that a short video programme about PD has been published by the Society, it will be helpful to discuss reactions to this before considering the next step. However, the advantages of video in presenting visual information about PD would be attractive to diverse audiences of children.

Future research on children having a parent with a complex neurological disability

One of the key benefits of the project has been an opportunity to develop new ideas and methods that will be of great relevance to future research. As our contacts have developed, the general topic of parents with complex neurological disabilities has begun to excite substantial interest. It has been already explained that the Bureau's application under the ESRC's 'Personal Welfare Management' research initiative was shortlisted for further consideration. Although necessarily conceived in haste, it has given us a good basis for exchanging ideas with other voluntary societies concerned with complex neurological disabilities. Discussions on new

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research plans will take place in the near future with a number of agencies and professionals. This gratifying result has been very much a tribute to the interest and commitment of the PDS which has been, we hope, a forerunner in its practical concern for the interests of children.

We have felt that the commissioning of this project on children has been very much a privilege for the National Children's Bureau and exploring such an innovative topic has been extremely worthwhile. The frequent resilience of children and their parents in the face of difficulties and uncertainties is sometimes, we feel, regarded too lightly but, especially in this case, deserves serious recognition from us all. We hope that the findings do some justice to the achievements of families in confronting the extraordinary, day by day. At the same time, the results should be a significant reminder of the responsibility of society to give due consideration to the needs of all children.

Project papers

'An assessment of psycho-social approaches to children of parents with chronic disease', British Sociological Association Medical Sociology Group Conference, 1990.

'From negative to positive: interpretations of children having a parent with complex disabilities' Scottish Concern (forthcoming).

'Younger children's perspectives on parents with Parkinson's disease'.

'The perspectives of young people having parents with Parkinson's disease'.

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